

**LATE(R) DIAGNOSIS OF ASC: USING PARENT NARRATIVES TO UNDERSTAND THE  
CONTEXTUAL FACTORS ASSOCIATED WITH LATER DIAGNOSIS AND ITS IMPACT ON  
CHILDREN AND FAMILIES**

**By**

**Fiona Eloise Cane**

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## **ABSTRACT**

‘Early diagnosis’ of Autism Spectrum Conditions (‘ASC’ hereafter) is often promoted as universally beneficial. Despite research identifying the earliest possible reliable diagnoses (at 14-24 months), many are diagnosed later in childhood, adolescence or adulthood. This study aims to: (i) explore the reasons for later diagnoses of ASC; and (ii) understand the impact of this on parents.

Narrative methodology (including narrative interviews), afforded the unique benefit of keeping individual, chronological stories intact. This allowed exploration of both explanatory narratives (reasons for later diagnosis) and descriptive narratives (impact of later diagnosis) of two parents of young people who had received a ‘later’ diagnosis of ASC (aged 12 years and 16 years).

Findings suggest that later diagnoses were interpreted to have arisen from a complex and highly individualised web of interacting factors. There were considerable differences in parental perceptions of the most beneficial time for the diagnosis, in hindsight. I advocate, therefore, an interactionist conceptualisation of ASC across the lifespan, and suggest that ‘early’ diagnosis is not always possible, necessary or beneficial. I invite further research to build upon these findings, with the ultimate aim of improving experiences and outcomes for children, young people and adults with autism and their families.

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## ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
AOD	Age of diagnosis
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CYP	Children and Young People (or Child and Young Person)
DCSF	Department for Children, Schools and Families
DFE	Department for Education
DfES	Department for Education and Schools
DOH	Department of Health
DSM	Diagnostic and Statistical Manual
EP	Educational Psychologist
IQ	Intelligence Quotient
NAPC	National Autism Plan for Children
NICE	National Institute for Health and Clinical Excellence
RQ1	Research Question One
RQ2	Research Question Two
SEN	Special Educational Needs
SENCo	Special Educational Needs Co-ordinator
SES	Socio-economic status

## CHAPTER ONE: INTRODUCTION

### 1.1 Background and Context

#### *1.1.1 Conceptualising Autism Spectrum Conditions*

Due to the enormous wealth of literature relating to autism, I begin by providing a context for the current research by briefly discussing definitions, and the evolving conceptualisations and diagnostic criteria of the condition, in order to set the scene for exploring diagnostic issues, particularly pertaining to the reasons for 'later' diagnoses and the impact on parents.

There are many answers to the question, 'what is autism?' which depend on the purpose of asking it (Happé, 1994), and, in my view, there is no simple, definitive answer. In attempting a simple explanation of a complex condition, I position 'autism' as a lifelong neurodevelopmental condition, which is heterogeneous in both aetiology and manifestation (National Institute for Health and Clinical Excellence; 'NICE', 2011). The latest diagnostic criteria in the Diagnostic and Statistical Manual ('DSM' hereafter; APA, 2013, p 50; Appendix 1) refer to "persistent deficits in social communication and social interaction" and "restricted, repetitive patterns of behaviour, interests or activities".

However, throughout history, there have been major changes in ideas about autism (Wing, 1996). Appendix 2 presents a brief outline of the pioneers, key milestones and changes to terminology and diagnostic criteria, which are discussed in detail by Feinstein (2010) and Wolff (2004). The history presented in Appendix 2 highlights the constantly 'evolving' (Matson and Jang, 2014) nomenclature and diagnostic criteria for autism. There also remains controversy about the accuracy of diagnostic criteria, in relation to their consistency with the latest research and practice (for discussion see: Matson and Jang, 2014; Ozonoff, 2012; Singer, 2012; Karim et al, 2012).

The nomenclature surrounding autism is confusing and constantly changing: 'autism', 'Autistic Spectrum Disorder' (ASD), 'Autistic Spectrum Condition' (ASC), 'Asperger's Syndrome', 'Pervasive Developmental Disorder- Not Otherwise Specified' (PDD-NOS), and 'atypical autism', to name a few. The terminology remains confusing, with little reported consensus between professionals (Karim et al, 2012). Furthermore, there is on-going debate as to whether autism is a singular heterogeneous disorder that has multiple aetiologies or whether 'the autisms' are a spectrum of distinct but closely related disorders (Waterhouse, 2013; Matson and Jang, 2014). The language of singular and plural forms is inconsistent, both between and within authors' work (Waterhouse, 2013). Although many authors still promote taxonomical distinctions, it is now generally considered that differentiating between different subtypes of 'ASD' is not only difficult to achieve, but also carries little clinical value (Szatmari, 2011). This is reflected in the latest DSM-5 criteria, which use one umbrella term, 'Autism Spectrum Disorder' (APA, 2013; Appendix 1), which also means that Asperger syndrome is no longer recommended to be diagnosed as a separate condition.

Some prefer the term 'Autism Spectrum *Condition*' as it recognises the disabling aspects of autism, but also that differences in functioning do not necessarily equate to disability (Baron-Cohen, 2008). This is linked to ideas about neurodiversity, which position atypical neurological development as part of normal human variation, requiring more tolerance and acceptance, rather than pathologising people with ASC (Bölte, 2011). The term 'ASC' sits within the social model of disability, which distinguishes 'impairment' from 'disability', suggesting that disability is constructed by society (Oliver, 1990). I adopt Autistic Spectrum Condition ('ASC' hereafter) as my preferred all-encompassing term, although I sometimes use 'autism' as an interchangeable shorthand, to reflect its continued use within the literature.

Interestingly, prevalence estimates have increased over time: autism used to be considered 'rare' at 4-5 in 10, 000 (Baron-Cohen, 2008), but recent US prevalence estimates at 1 in 110 children (Lord and Bishop, 2010) and 1.7% of children in the UK (Russell et al, 2014). This begins to raise philosophical questions about whether autism was always 'there' and we are getting better at 'discovering it', or whether our evolving ideas and definitions of autism are leading to more people being identified as 'having' autism or being included within the clinical range of the 'autism spectrum'.

The evident evolution of ideas about autism has led me to adopt a social constructionist view of the condition. Verhoeff (2013) argues that most histories of autism are implicitly positivist, presenting a chronological, linear and progressive development towards *the* current understanding of autism, in which the contemporary view is considered the factual end-point. Most literature takes an essentialist view of ASC as a static and decontextualised 'thing', which has always existed, but that is now discoverable by science (Verhoeff, 2013). Nadesan (2005) argues that these assumptions have promoted the application of a medical model to autism research, in which the search for the aetiology takes precedence, with the ultimate aim of finding a 'cure'. The aetiology of autism has been widely researched, and despite many biological and psychological theories, some of which are supported by research evidence (see: Baron-Cohen, 2008; Happé, 1994; Jordan, 1999; Roth, 2010; Bölte and Hallmayer, 2011), there is still no universal, unifying explanation.

Some, within the ASC research community, argue that this medical model may limit research opportunities to understand the condition and the people who are affected (Verhoeff, 2013; Nadesan, 2005). Likewise, I adopt a social constructionist conceptualisation of the condition. This does not deny the biogenetic component of ASC, but acknowledges the role of social factors in shaping conceptualisations of autism, how it is experienced and what it means to people (Nadesan, 2005). Similarly to Russell (2010), I have adopted an interactionist perspective to conceptualise ASC as both a



biologically and socially determined condition, and I agree with Vacanti-Shova's (2012) application of a developmental psychopathology model, in which the interplay between biological, psychological, and social-contextual aspects of child development is acknowledged (Cicchetti and Toth, 2009).

My aim, therefore, is not to deny the value of the on-going biological, neurological and genetic research; rather to reject the "positivist and essentialist understanding of autism as a discrete and stable entity in nature" (Verhoeff, 2013, p. 455) and instead, to promote a social constructionist epistemological approach in autism research, which may offer some useful insights from an alternative perspective. Finally, I am persuaded by Nadesan's (2005) argument that, instead of simply asking 'what *is* autism?' research should adopt a social constructionist approach to exploring how autism is experienced and what it means to people.

#### *1.1.2 How is ASC diagnosed?*

Given the complex and heterogeneous manifestations of ASC, together with the constantly evolving conceptualisations and diagnostic criteria and controversies regarding aetiology, diagnosing the condition remains a challenge (Jordan, 1999; Yates and Le Couteur, 2013). Unsurprisingly, there is no fail-safe, unequivocal 'test' for diagnosing ASC. Good practice guidance seeks to improve the consistency, efficiency and transparency of diagnosis (National Autism Plan for Children, 'NAPC', 2003; NICE, 2011). NICE (2011) guidance recommends setting up multi-agency strategy group in local areas, responsible for the recognition, referral and diagnosis of children and young people ('CYP' hereafter). The assessment process should include a pooling of information from all sources, and may include standardised assessment tools, although NICE (2011) suggests that they are neither necessary nor sufficient. In a research study, Lord and Luyster (2006) concluded that clinical judgement is essential,

which is reflected in NICE (2011) guidance. NICE guidelines (2011) also highlight the importance of considering individual functioning, a framework for which is provided in DSM-5 criteria (APA, 2013, p. 52; Table 1). This outlines three severity levels relating to the impact on functioning and contingent support required, which is a step towards adopting a bio-psycho-social model of ASC, though there are many more contextual and situational factors in determining the nature and severity of difficulties experienced by individuals with ASC, which are not yet acknowledged by DSM-5 criteria (APA, 2013).

Table 1: DSM-5 (APA, 2013) severity levels for ‘autism spectrum disorder’

<b>Severity Level</b>	<b>Social communication</b>	<b>Restricted, repetitive behaviours</b>
<b>Level 3:</b> “Requiring very substantial support”	<ul style="list-style-type: none"> <li>• “severe deficits”</li> </ul>	<ul style="list-style-type: none"> <li>• “severe impairments in functioning”</li> <li>• “extreme difficulty coping”</li> <li>• “interfere with functioning in all spheres”</li> <li>• “great distress/difficulty”</li> </ul>
<b>Level 2:</b> “Requiring substantial support”	<ul style="list-style-type: none"> <li>• “marked deficits”</li> </ul>	<ul style="list-style-type: none"> <li>• “frequent enough to be obvious”</li> <li>• “distress and/or difficulty”</li> </ul>
<b>Level 1:</b> “Requiring support”	<ul style="list-style-type: none"> <li>• “noticeable impairments”</li> </ul>	<ul style="list-style-type: none"> <li>• “significant interference with functioning”</li> </ul>

This graduated approach to describing severity levels also highlights an interesting debate about the boundaries between clinical and sub-clinical presentation and individual differences in how ASC may be experienced in relation to social and environmental influences. My practice as a (Trainee) Educational Psychologist and approach to assessment and case formulation has been shaped by Engel’s (1977) bio-psycho-social model, which considers social, psychological and behavioural components of a condition or presenting issue. The model, Bolton (2014) explains, consists of ‘the four P’s: Preconditions (i.e. biological predispositions), Precipitating factors (i.e. events happening before or at the time of the presenting problem), Perpetuating factors (i.e. factors that maintain the problem) and Protective factors (i.e. factors that make the situation better). Brody (2014) supports this approach, suggesting that we need a more storied approach to case formulation. I have applied this

model to my conceptualisation of ASC, and consider that there are important social and contextual factors that influence the extent to which people with ASC (and those with similar 'sub-clinical' presentation) experience difficulties.

The concept of severity levels also highlights the issue of whether the diagnosis is considered necessary and/or beneficial. Lauchlan and Boyle (2007) offer a useful discussion of the pros and cons of diagnostic labels for those with special educational needs. Firstly, they argue that whilst a diagnosis may be seen as a gateway to treatment or resources, it may not always be a clear linear pathway to specific and effective interventions, perhaps even resulting in simplified pathways (e.g. label = special school) and less consideration of the *individual's* needs. Secondly, Lauchlan and Boyle (2007) suggest that labelling may lead to increased awareness and understanding of particular difficulties, although their counter argument suggests that increased stigmatisation may be experienced. Thirdly, the authors debate whether diagnostic labels serve to reduce ambiguities and improve professional communication, or, conversely, whether labels lead to generalisation of individual difficulties and reduced consideration of individual needs. Fourthly, the authors suggest that labels may provide comfort and helpful explanations for families, whilst cautioning that this may also lead to focusing on within-child deficits and lowered expectations. Finally, Lauchlan and Boyle discuss the potential advantage of a diagnosis in providing an identity and sense of belonging to a social group, contrasted with the potential social disadvantages, including teasing, bullying and low self-esteem. Overall, the authors give the opinion that the disadvantages outweigh the advantages of diagnostic labels, although they do acknowledge their utility and helpfulness in some individual cases. Their main recommendation is that children, young people and their families should be given the opportunity to accept or reject a label, prior to the decision being made (Lauchlan and Boyle, 2007): I consider this to be a highly valuable and ethically sound principle for practice, although conflicting views within families may raise further need for ethical debate.

Within the local authority of the current study, the NICE (2011) guidelines have been implemented: with a well-established multi-agency<sup>1</sup> diagnostic panel. Referrals can be made by any professional (including via parents) within children's services. If the referral is deemed appropriate after screening by the Chairperson, a keyworker is assigned and information is gathered, including core elements from NICE (2011) guidelines<sup>2</sup>. Diagnostic decisions are made based on multi-agency agreement following case discussion, including elimination of differential diagnoses.

### *1.1.3 When can ASC be diagnosed?*

There is a strong narrative in existing research, which suggests that there *is* an earliest age at which autism can (and should) be diagnosed. This evidence, mainly from the USA, suggests that autism can be reliably diagnosed at around 2-3 years, with evidence of diagnostic stability at follow-up within the following 1-2 years (Eaves and Ho, 2004; Kleinman et al, 2008; Lord, 1995; Moore and Goodson, 2003; Stone et al, 1999), and even over 2-9 years (Lord et al, 2006). One review reported 68-98% diagnostic stability rates for positive ASC diagnoses over time (Vacanti-Shova, 2012). Many researchers seek to identify and diagnose autism at increasingly younger ages. For example, Stone et al (2008) report that the 'Screening Tool for Autism in Two-year-olds' (a 12-item interactive measure of social-communicative behaviours) can be used effectively for children as young as 14 months. Other evidence suggests that although subtle early social abnormalities may be present at sub-clinical levels (acknowledged with hindsight), ASC cannot be unequivocally detected before the age of 12 months (Pierce et al, 2009).

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<sup>1</sup> This includes representation from: educational psychology, clinical psychology, paediatrics, social care, psychiatry, speech and language therapy, and occupational therapy.

<sup>2</sup> This includes: medical history, medical examination, developmental history, educational assessment and observation, communication assessment and standardised diagnostic tools where relevant.

This research also tends to be limited by its use of high-risk samples: those with a sibling who has ASC or those already identified as having communication or social difficulties (Guthrie et al, 2013). Lord and Luyster (2006) argue that, based on existing research, we cannot draw reliable conclusions about the diagnostic trajectory of: (i) children who *do* present with autism symptoms but *are not* referred or, (ii) children with milder difficulties who are referred at a later age.

I am better persuaded by the arguments of more tentative authors, who argue that the earliest age of confident diagnosis is limited by the stipulation that autism is a behaviourally defined disorder (Pierce et al, 2009). Early detection of ASC is complicated by its clinical heterogeneity and effective strategies for early identification are not yet established: Zwaigenbaum (2012) cautions about the possibility of misclassification (false positives and false negatives). Matson et al (2008) argue that there is likely no 'magic cut-off' for early identification. Despite the volume of research into diagnosis in early childhood, many are diagnosed later, including during adolescence and adulthood, although the numbers are unknown (Gallo, 2010).

Progressing from the historical diagnostic criterion that specified an onset before 30 months (DSM-III, APA, 1980), many current texts embrace a lifespan perspective, suggesting that features of ASC may manifest differently at different ages (Frith, 2003; Karim et al, 2012) and that behavioural profiles may change with age (Yates and Le Couteur, 2013). Frith (2003) postulated that not only does autism affect development, but development also affects autism. Some authors suggest that features of ASC may not be present, noticeable or cause concern in early childhood, and suggest that certain features may not manifest until later (Frith, 2003) or until influenced by social and contextual factors in the person's environment. NICE (2011) guidelines, in line with DSM-5 criteria (APA, 2013), suggest that where autism is not suspected until later, potential early 'signs' of autism (as may be evident in other cases)

may have been masked by strong coping mechanisms and/or a supportive environment. Furthermore, NICE (2011) guidance suggests an interactionist approach, in recognising that whilst 'core' autism features usually present in early childhood, they may not become apparent until situational factors prompt a change.

Although ASC diagnoses *are* sometimes made later in childhood, my literature searches (Section 2.2) revealed that research with this population is sparse. Indeed, the keyword 'early' revealed a multitude of research, yet the keywords 'late/r' and 'delay/ed' often yielded no results. By contrast, the mantra of 'early diagnosis' and 'early intervention' is embedded and many papers assert benefits without primary reference to empirical evidence. This raises concerns that the 'prevailing wisdom' (Matson et al, 2008) of the benefits of early diagnosis and intervention may be perpetually echoed throughout the literature without critical challenge: this warrants brief exploration of research evidence.

The argument for early diagnosis to facilitate early intervention has high face validity. The idea of a critical period is argued by Bradshaw et al (2015), who outline the rapid social development that typically occurs in the first two years, in which, they argue, early intervention could narrow the gap between those with or at-risk of ASC and their typically developing peers. Controversially, these arguments have been challenged due to the lack of empirical evidence to support intervention: "the arguments put forth, while compelling, are largely unsubstantiated by data" (Matson et al, 2008, p. 81). Despite the widespread agreement about the desirability of early intervention for ASC, "there is surprisingly little hard evidence to support this view" (DfES, 2004, p. 9). Fundamentally, early diagnosis should not be considered an end in itself: it can only be beneficial if there are appropriate interventions and support services available (Osborne et al, 2008; Stone et al, 1999). In practice, the race to promote increasingly younger detection of ASC seems to have overtaken efforts to develop evidence-supported early interventions for infants under 2-3 years (Bradshaw et al, 2015; Wallace and Rogers, 2010).

A comprehensive review of early intervention evidence is beyond the scope of this review, but papers returned from the original searches and a separate search for review papers revealed surprisingly tentative findings (for example: Fernell et al, 2013; Eikeseth, 2009). Evidence suggests that the differential benefits derived by CYP with ASC from early intervention may be influenced by several biological and environmental factors, including: age, language abilities, autism severity, maternal age and education (Ben-Itzhak and Zachor, 2011). Williams and Brayne (2006, p. 11) conclude that “there is insufficient evidence regarding the effectiveness of interventions”, and highlight the need for further outcomes-based research.

Furthermore, in order to conclude that ‘early intervention’ is superior to ‘later intervention’, research must indicate a difference in outcomes based on age at the start of intervention. The current literature review found remarkably little research directly assessing this, perhaps due to the ethical challenges of controlled studies in which the start of intervention is intentionally delayed. However, quasi-experimental studies may be permissible: one such doctoral thesis study found that younger age (range 6-44 months) at diagnosis (and therefore the start of intervention), in conjunction with the intensity of intervention (measured in hours per week), was associated with significantly higher Vineland Adaptive Behaviour Scale scores at follow-up (Vacanti-Shova, 2012). One strength of this study is the wider conceptualisation of ‘early intervention’ to include not only targeted interventions (such as Applied Behaviour Analysis), but also parent checklists of services received (such as speech and language therapy and/or occupational therapy). However, this highlights a major challenge in the field. Whilst there is still a call for the cost-effectiveness of interventions to be researched (Zwaigenbaum, 2012), as the DfES (2004) paper indicates, the multi-dimensionality of ASC alongside the complex and diverse combinations of approaches to ‘early intervention’ means that measuring

outcomes, ascribing change to any particular intervention and achieving consistency between studies is an almost insurmountable task.

## **1.2 Broad rationale**

Overall, despite the embedded rhetoric and convincing arguments about benefits of early diagnosis, research evidence about the most appropriate 'early intervention package' is still tentative. Primarily, this indicates a need for research to identify the most effective intervention and support packages, but it also highlights other important gaps in the literature.

Efforts to promote the earliest possible diagnosis have neglected to consider the contextual factors associated with age of diagnosis ('AOD' hereafter) and possible reasons for later diagnoses. This begs the question: if ASC *can* be diagnosed reliably as early as 2 or 3 years, why does this not happen in all cases? Furthermore: is the ultimate aim to diagnose all cases earlier? Some argue that clinical practice should seek to close the gap between when children can be identified and when diagnosis actually occurs (Shattuck et al, 2009). The essentialist view of autism proposed by the dominant medical model suggests that later diagnoses result from missed opportunities for recognition and referral, perhaps due to lack of professional knowledge and/or parental awareness. Alternatively, applying a bio-psycho-social model (see: Brody 2014; Engel, 1977; Bolton, 2014) affords the consideration that although with hindsight there may have been subtle signs of autism, functioning is not considered to be impaired until later, perhaps triggered by situational/contextual factors. I am curious about whether cases of later diagnosis are considered to be 'missed diagnoses' which could be eliminated by improved professional training and public awareness, or alternatively whether a lifespan approach would afford



consideration of different manifestations at different ages and the influence of social/contextual factors on the level of impairment from the sub-clinical to clinical range (DSM-5, APA, 2013; Table 1).

Moreover, given the resonating emphasis on the benefits of early diagnosis (despite tentative evidence) and that promoting 'early intervention' remains a key aim of the NICE (2011) guidance, I also question the perceived impact of *later* diagnosis of ASC on CYP, parents and families: is later diagnosis necessarily negatively experienced? In the current study, I chose parents, rather than CYP, as suitable 'informants' (Shedki, 2005) about experiences of later diagnosis (my full rationale is articulated in Section 3.8.1). The parental perspective is therefore focused upon in Chapter Two.

This calls for exploratory (and explanatory) research to understand the circumstances in which later diagnoses of ASC are given, and descriptive research to understand the impact of this (for parents, in the current study).

### **1.3 Development of research ideas**

This research developed primarily out of my own interest and career specialism in autism. I initially trained as a primary school teacher and taught for two years in a mainstream primary school. During this time, I worked alongside the school's educational psychologist and multi-disciplinary team to support and include four boys with autism: two were previously diagnosed and two were assessed and diagnosed during time in my class. I then worked as a specialist teacher for autism at a special school in London, where I taught and supported pupils with autism, working closely with the multi-disciplinary team (educational and clinical psychologists, occupational therapists and speech and language therapists) to understand the functional and communicative aspects of their behaviour.

These early career experiences inspired me to pursue a career in Educational Psychology and shaped my approach to working with CYP with ASC. During my three years' doctoral training, I have continued to develop a special interest in autism research and practice. In my second year, I was based within a special school for pupils with autism. The role included solution-focused consultation work with teaching and support staff, as well as parents, including functional behavioural analysis. I also undertook some direct work with CYP, including eliciting pupil views (for example about preferred environments, lessons or approaches to supporting them) and therapeutic work, using solution-focused and cognitive-behavioural approaches.

Furthermore, I developed my specialism at a strategic level by shadowing my placement supervisor, who held the position of strategic lead for ASC, which included chairing the autism diagnostic panel and co-ordinating assessment and support for ASC across the authority. I joined the Local Authority's 'Autism Strategy Group', which identified an interesting priority for development: supporting parents of children who had been diagnosed with autism 'later'. At the time the Local Authority offered 'EarlyBird' and 'EarlyBird Plus' parent support programmes; promoted by the National Autistic Society (NAS, 2015a; NAS, 2015b), and supported by research evidence (Shields, 2001; Halpin, Pitt and Dodd, 2011; Clubb, 2012; Cutress and Muncer, 2013; Silvey and Mak, 2009), the psycho-education programmes offer meetings and home visits over a period of 10-12 weeks. The 'EarlyBird' programme is targeted at parents of pre-school children (NAS, 2015a) whilst the 'EarlyBird Plus' programme is aimed at parents of children aged 4-8 years (NAS, 2015b). The Local Authority's strategy group suggested that more support was needed for parents of children who were identified and diagnosed in older age groups.

Upon engaging with the existing research literature, I discovered an overwhelming focus on *early* identification, *early* diagnosis, and *early* intervention, with very little existing research into CYP (and their parents) who had received a 'later' diagnosis. As a result, I proposed to the strategy group members that, before trying to create *support* programmes for these parents, more initial research was needed to understand the reasons for later diagnosis and to understand and gain insights into parents' experiences of this. This is in-keeping with my professional values of listening and empowerment and I believe this research to be important in beginning to understand people's experiences, rather than simply 'imposing' a support programme which may not be appropriately tailored to the needs and experiences of these parents.

#### **1.4 Relevance to EP role**

In an early paper, Waite and Woods (1999) commented on the role of EPs in assessing the educational needs of children for whom autism is suspected. They described a growing need to establish multi-disciplinary teams to identify and assess autism, and argued that EPs should be placed centrally. Subsequently, this role was formally recognised by guidance documents (NAPC, 2003; NICE, 2011). Clinical and/or educational psychologists should be represented in local multi-disciplinary autism teams, or at least provide information as required (NICE, 2011). EPs (and clinical psychologists) can offer psychological knowledge, observation and assessment skills (Waite and Woods, 1999), as well as the application of hypothesis-testing approaches to exploring differential diagnoses, which are important in assessing for possible autism (NICE, 2011).

Furthermore, NICE guidance (2011) highlights the importance of information about the child's presentation in multiple settings; EPs may make a further distinctive contribution by visiting the CYP within the educational setting or at home, rather than in a clinic (Karim et al, 2012). Waite and Woods

(1999) suggested that EPs should develop a consistent role in relation to autism, akin to a 'whole profession view'. Since then, the British Psychological Society (BPS, 2006) defines the role to include not only identification and assessment, but also intervention and post-diagnostic support, multi-agency working, service development, training, supervision, research and audit work.

According to the BPS position paper (2006), the EP role in relation to autism assessment can be conceptualised on two 'tiers': (i) a universal need for EPs to have adequate knowledge, skills and awareness in relation to ASC; and (ii) a specialist EP role for ASC to include training professionals, supporting parents and strategic-level service development. Whilst the NAPC (2003) promotes the 'expert' role of EPs, it is unclear whether this positions all EPs as 'experts' or suggests the need for a specialist role. Waite and Woods (1999) suggested that some EPs could develop this specialism, as in the Local Authority of the current study. Through both my previous professional experience as a specialist teacher for ASC, and my current doctoral level research and training, it is also my professional aim to develop a specialist role for ASC in my career as an EP.

## **1.5 Overview of structure and content**

In Chapter One I provide a broad rationale for original research to explore the circumstances in which later diagnoses of ASC are given and the impact on parents; relevant existing literature is reviewed in Chapter Two. Chapter Three outlines the current study's social constructionist assumptions and describes the contingent application of narrative methodology. In Chapters Four and Five, I discuss the findings and implications arising from each of the current study's research questions (detailed in Section 3.2). Finally, in Chapter Six, I discuss the current study's contribution to research and practice, evaluate its trustworthiness and dependability (validity and reliability), and consider its limitations.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Chapter overview**

In this literature review, I discuss existing research in relation to two key areas arising from the rationale in Chapter One: the first seeks to explore existing research into the reasons for later diagnoses of ASC, and the second aims to explore the impact of these on parents. Despite my social constructionist conceptualisation of ASC articulated in Chapter One, the majority of research literature reflects a more positivist tradition, which I discuss, whilst reflecting on its epistemological and methodological limitations. I aim to identify theoretical and/or empirical gaps in existing knowledge (Knopf, 2006). This ‘scoping’ purpose (Jesson et al, 2011) of the current review aims to provide a context and rationale for the current research study.

### **2.2 Search strategy**

For this narrative, traditional review (including literature in Chapter 1) I initially used systematic keyword searches in two databases, ‘ProQuest Social Sciences’ and ‘Autism Data’, using combinations of search terms presented in Table 2. Some terms were pre-defined keywords suggested by the Autism Data search function. Where further relevant research was identified within the papers returned, an iterative approach was employed, in order to maximise inclusion of relevant literature. Books were sought using similar search terms on the University of Birmingham’s library search facility and an online book retailer.

*Table 2: Outline of keywords used during initial literature searches*

<b>Autism</b>	<b>Age of Diagnosis</b>	<b>Impact of Diagnosis/ Living with ASC</b>
autis*	"age of diagnosis"	impact
ASD	"age at diagnosis"	experien*
ASC	"early diagnosis"	diagnos*
Asperger*	"early identification"	"living with"
	"late diagnosis"	parent*
concept*	"later diagnosis"	narrat*
construct*	"delayed diagnosis"	
histor*	"age of onset"	
defin*	"early onset"	
diagnos*	"late onset"	
	"early intervention" AND review	
<i>Boolean logic rules:</i>		
<ul style="list-style-type: none"> <li>• Asterisks were used to search for word stems (for example, autis* would return results for 'autism' and 'autistic').</li> <li>• Inverted commas were used to search groups of unseparated words (for example, "living with" would not search 'living' and 'with' as separate terms).</li> </ul>		

To further specify inclusion and exclusion criteria, initial searches included results up to February 2015, with no early date limit. As a large proportion of autism research emanates from the USA, international research was generally included, unless the abstract indicated that the conclusions were specific to a particular country's practices. Research was included from both peer reviewed journals and unpublished doctoral theses.

### **2.3 Age of diagnosis: 'early' versus 'late'**

This section of the literature review explores existing explanatory research into the reasons for variation in AOD. Existing research has primarily sought to identify 'factors' associated with AOD, including one noteworthy systematic review by Daniels and Mandell (2013). A number of potential hypotheses have been explored. My review adopts a narrative style, exploring the factors that explain variance in AOD. Based on my review of the literature, I discuss the influences on AOD in relation to

three broad areas: (i) demographic factors; (ii) interactions between child presentation and parental concerns; and (iii) professional factors and service variation.

Interestingly, despite there being no agreed designations of 'early' or 'late' diagnosis, existing research typically conceptualises arbitrary cut-offs between 'early' and 'late', often at comparatively young ages (for example, 18 months: Baghdadli et al, 2003; 3 years: Twyman et al, 2009; 6 years: Jónsdóttir et al, 2011). Indeed, some diagnoses may not be made until much later, during adolescence and even adulthood (Gallo, 2010), indicating a gap in research with (parents of) CYP who receive a 'considerably later' diagnosis of ASC (e.g. during adolescence).

### *2.3.1 Demographic factors*

It has been hypothesised that family factors, such as birth order and sibling status (whether or not diagnosed with ASC) may influence AOD, perhaps reflecting parental experience of ASC and/or knowledge of typical development. Evidence suggests that being first born may be a risk factor for later diagnosis (Fountain, 2011; Rosenberg et al, 2011), whilst reciprocally, having an older sibling is associated with earlier diagnosis (De Giacomo and Fombonne, 1998), perhaps reflecting parental experience of typical development. Having an autistic older sibling (Adelman, 2010; Mishaal et al, 2014; Herlihy et al, 2015) or having relatives with autism (Twyman et al, 2009) is associated with younger AOD, perhaps reflecting parental recognition of ASC. One recent study reported a significantly lower age of first parental concern (10 months) when there was a sibling with ASC, but slightly later (14 months) when there was a typically developing sibling and even later (16 months) when the child had no siblings (Herlihy et al, 2015). This finding is not entirely supported; other research reports null findings in relation to birth order (Twyman et al, 2009), or having a previous child diagnosed with ASC

(Mishaal et al, 2014). Similarly, findings from a systematic review reveal mixed results: out of six studies, one reported that first-born children were diagnosed earlier, three found they were diagnosed later and two studies found no association with birth order (Daniels and Mandell, 2013). Parental age has been used as a measure of parental experience or education, again with mixed results. Whilst some studies report no association (Mishaal et al, 2014; Daniels and Mandell, 2013: four studies), others suggest that earlier diagnosis was positively correlated with maternal age (Daniels and Mandell, 2013: one study; Frenette et al, 2011). This mixed evidence suggests other factors must be at play.

Given the unbalanced reported gender ratio of 5:1 (male: female; Russell et al, 2014), there is a wealth of research into gender and ASC, yet more mixed findings about the association with AOD. One study reported that being male was associated with younger AOD (Shattuck et al, 2009) and three studies from Daniels and Mandell's (2013) review supported this, but others suggest that parental first concerns occur significantly earlier for females (Horovitz et al, 2012; Daniels and Mandell, 2013: one study), perhaps because delays in girls' language is more atypical (Rosenberg et al, 2011). Despite this, several studies have concluded that AOD is not associated with gender (De Giacomo and Fombonne, 1998; Mishaal et al, 2014; Twyman et al, 2009; Daniels and Mandell, 2013: 13/17 studies).

Some authors have hypothesised about the influence of socio-economic status ('SES' hereafter) on AOD. Evidence generally indicates that those with higher SES receive an earlier diagnosis (Daniels and Mandell, 2013), measured by greater household income (Daniels and Mandell, 2013; two studies), and higher parental education (Fountain, 2011; Rosenberg et al, 2011; Daniels and Mandell, 2013: four studies). Conversely, children described as 'near-poor' tended to receive a diagnosis 0.9 years later than children in families with incomes more than 100% above the poverty level (Mandell et al, 2005). Similarly, one study reported that children eligible for Medicaid (a US social health care programme for low-income families) tended to be diagnosed later (Daniels and Mandell, 2013). Despite this,



children eligible through the poverty category tend to be diagnosed earlier than those eligible through other categories, including disability or foster care (Mandell et al, 2010), suggesting other contributory factors. Again, there is evidence of null findings of an association between AOD and SES (De Giacomo and Fombonne, 1998; Daniels and Mandell, 2013: six studies) or parental educational attainment (Mishaal et al, 2014).

Many studies have investigated whether AOD is influenced by race and ethnicity. Generally, findings indicate that those from non-white ethnic backgrounds tend to be diagnosed later. One large-scale (n=17 185) US study found that non-white or Hispanic families tended to receive a later diagnosis (Fountain, 2011), and another study reported that African American children received a diagnosis approximately 6 months later than the White children (Perryman, 2009). This is supported by Twyman et al (2009), who reported that Hispanic and African-American children, and/or those with mothers born outside the US are more likely to be diagnosed after the age of 4 years (considered a 'later' diagnosis). These findings are mostly corroborated by the conclusions of Daniels and Mandell's (2013) review, although five studies reported no association. Finally, Rosenberg et al (2011) did not report clinical differences, but demonstrate a possible vulnerability in ethnic minority groups. Current research has not offered sufficient explanations for these findings. The idea of cultural differences in parental concern is unsupported: Jang et al (2014) reported no racial/ethnic differences in the age of parents' first concerns and Perryman (2009) reported no differences in severity of parental concern or attribution of symptoms based on ethnicity. Alternatively, there may be issues with equality of access to services and/or professional attributions, which warrant further research.

### *2.3.2 Child presentation and parental concerns*

Due to the complex and heterogeneous nature of ASC, many have hypothesised that child presentation factors may influence AOD: the role of co-morbidity and alternative diagnoses is particularly interesting. Some evidence suggests that receiving a non-ASC diagnosis prior to the ASC diagnosis is a risk factor for later ASC diagnosis (Adelman, 2010; Daniels and Mandell, 2013). Supporting this, evidence suggests that of those in the 'later' diagnosis group (diagnosed after 6 years), around half had received other developmental diagnoses previously (Jónsdóttir et al, 2011). In particular, ADHD diagnoses have been associated with an increase of 1.29-years in AOD (Frenette et al, 2011). Hearing impairment, oversensitivity to pain and psychiatric or neurological conditions have also been associated with later AOD (Daniels and Mandell, 2013; Mandell et al, 2005). Some studies suggest that later AOD is common in children with co-occurring health conditions or if parental first concerns are medical (Daniels and Mandell, 2013), although Jónsdóttir et al (2011) reported null findings. Other evidence, however, suggests that medical problems may lead to an earlier ASC diagnosis (Rosenberg et al, 2011).

Studies into the effects of co-morbid intellectual disability or IQ (Intelligence Quotient) on AOD also produced mixed findings. Research demonstrates that children with a lower IQ or co-morbid intellectual disability tend to be diagnosed earlier (Jónsdóttir et al, 2011; Shattuck et al, 2009; Rosenberg et al, 2011; Daniels and Mandell, 2013). However, one study reported the converse: intellectual disability was associated with later AOD (Daniels and Mandell, 2013) and four studies found no association (Daniels and Mandell, 2013). These contradictory findings could be explained by two possibilities. Perhaps earlier parental concerns (although not ASC-specific) due to more overt medical problems, delay in developmental milestones (De Giacomo and Fombonne, 1998; Baghdadli et al, 2003) or intellectual/cognitive function prompts earlier professional involvement and therefore

opportunity for earlier recognition. Alternatively, co-existing conditions (whether medical or developmental) might mask the ASC symptoms, particularly where there is a high degree of symptom overlap.

Research suggests that CYP presenting with a greater number of autism-specific symptoms (Daniels and Mandell, 2013) and higher severity of social interaction impairment (Mishaal et al, 2014) are likely to be diagnosed earlier. One study found that children with all 12 behavioural features of 'ASD' (using DSM-IV-TR criteria) tended to be diagnosed earlier (mean: 3.8 years), than those with only seven behavioural features (mean: 8.2 years; Maenner et al, 2013). Another study reported trends, although not significant, that mean CARS scores (Childhood Autism Rating Scale: a measure of symptom severity) were slightly higher for the early diagnosis group (Twyman et al, 2009). Only one study reported null findings between AOD and symptom severity using the ADI-R (Autism Diagnostic Interview-Revised; Jónsdóttir et al, 2011). Reciprocally, it has been hypothesised that those with milder, more subtle symptom presentation may receive a later diagnosis. This is supported by findings that those with higher communication function (Fountain et al, 2011) and close to normal adaptive functioning (using Vineland Adaptive Behaviour Scales; Mishaal et al, 2014) are more likely to be diagnosed later.

Some researchers have explored whether AOD is associated with *qualitative* differences in the child's presentation. It seems that ASC-specific symptoms (e.g. concerns about language, social skills and atypical behaviour) are associated with earlier diagnosis (Twyman et al, 2009; Barrie, 2010; Daniels and Mandell, 2013; Jónsdóttir et al, 2011; Mandell et al, 2005). Conversely, in cases where first noted concerns were non-autism-specific behavioural difficulties, children are more likely to be diagnosed later (Adelman, 2010), although Barrie (2010) reported that those with initial 'behavioural concerns' were split equally between early and late diagnosis groups. In cases where ASC symptoms are

attributed to non-ASC behavioural problems, later diagnoses are likely (Perryman, 2009; Daniels and Mandell, 2013: two studies).

The presence of overt characteristics such as unusual mannerisms or atypical behaviours, such as toe walking, hand flapping and sustained odd play, are associated with earlier AOD (Twyman et al, 2009; Valicenti-McDermott et al, 2012; Mandell et al, 2005) and children with specific impairments in nonverbal communication, pretend play, inflexible routines, and repetitive motor behaviours also tend to be diagnosed earlier (Maenner et al, 2013). In addition, developmental regression (loss of previously acquired skills) has been associated with earlier diagnosis in several studies (Adelman, 2010; Mishaal et al, 2014; Valicenti-McDermott et al, 2012; Daniels and Mandell, 2013; Jónsdóttir et al, 2011; Shattuck et al, 2009). Just one study reported no association between AOD and repetitive and unacceptable social behaviour (Fountain et al, 2011).

Certain patterns of child symptom presentation are associated with later AOD. Although there is controversy surrounding the sub-groups of ASC, evidence suggests that children diagnosed with 'Asperger's Syndrome' were diagnosed later (average 7.2 years) than those diagnosed with 'autistic disorder' (average 3.1 years; Mandell et al, 2005). This is supported by Rosenberg et al (2011), who considered this to be a 'milder' presentation, resulting in later recognition, although this conceptualisation of Asperger's syndrome as a *milder* form of autism should, in my view, be challenged. Later AOD is also associated with impairments in peer relations, conversational ability, and idiosyncratic speech (Maenner et al, 2013): these features may only be observable at later stages. This highlights a challenge in recognising ASC. As a behaviourally-defined condition, these ASC symptoms do not 'exist' in isolation: they must be interpreted by parents, carers and professionals through the 'lens' of ASC. Notably in one study, signs of more ASC-specific behaviours did not influence age of parental recognition (De Giacomo and Fombonne, 1998) and in another study, parents who expressed

general concerns, tended to receive a later diagnosis of ASC, despite reporting being worried earlier (Guinchat et al, 2012).

There is clearly a link between child presentation and first parental concerns. Guinchat et al (2012) suggest that the *type* of first concerns noted by parents vary with age: motor problems and passivity were reported in the early awareness group (14.6 months); emotional, hyperactivity, and sleep problems were noted by parents in the intermediate awareness group (15.3 months); and communication problems, poor social interaction, and “autistic-type behaviours” were noted by parents in the later awareness group (22.3 months).

Evidence suggests that when the *age* of parental first concern is earlier (mean= 16 months) children tend to be diagnosed younger (before 30 months), whereas later parental concern (mean= 25 months) was associated with later diagnosis (after 30 months; Barrie, 2010). This is, however, unsupported by Jónsdóttir et al’s (2011) null finding: age of first parental concern and age of first autistic symptoms (on hindsight) were not associated with AOD. Greater severity of parental concern about the child’s initial symptoms has been associated with earlier AOD (Perryman, 2009; Daniels and Mandell, 2013: one study). However, Barrie (2010) reported that in some cases there was a delay between parents’ first concerns and help-seeking, with parents who were concerned earlier tending to wait longer to seek help. Some parents may notice early signs, such as unusual behaviour, without being concerned enough to seek advice or having the knowledge to make the connection to autism (Molina, 2014): parental factors may also contribute to delays in diagnosis with individual differences in parental concerns and help-seeking behaviours.

### *2.3.3 Professional factors and service variation*

There is evidence from the USA that AOD varies according to geographic location, suggesting that AOD may be affected by local policies and resources (Daniels and Mandell, 2013). Findings indicate that children may be diagnosed later if they live in large urban or rural areas, compared to children living in small urban or suburban areas (Mandell et al, 2010). One previous UK study found no difference in AOD based on place of residence (De Giacomo and Fombonne, 1998), although my literature search did not return any more recent UK research. These findings suggest a need to develop services further in more rural areas (Rosenberg et al, 2011), although Mandell et al (2010) conclude that variation in AOD is more attributable to child-level variables, than to state policies and resources.

Delays in the diagnostic process may contribute to later AOD. Research indicates that the diagnostic period averages nearly 2 years in one UK study (Rose, 2011) or even up to 3 years in one Canadian study (Siklos and Kerns, 2007). In a previous large UK survey, the average wait was about 4 years, with about one quarter of parents (n=1300) waiting up to 12 months, approximately 10% waiting up to 2 years and, in one case, waiting 10 years (Howlin and Moore, 1997). Mann (2013) suggests that delays may be related to: professional dismissal of parent concerns; parent or professional lack of knowledge; parental denial or delayed action; administrative barriers; limitations in diagnostic services; geography; and family finances.

Professional dismissal is considered by parents to be a barrier to securing a diagnosis (Mann, 2013). In one study, Howlin and Moore (1997), reported that around 25% of parents (n=1,300) were reassured 'not to worry', 6.5% were told to return if problems persisted and 4.2% were told that the child would 'grow out of it'. This is echoed by Rose (2011), who reported that approximately 20% of parents reported that their initial concerns were dismissed by the consulting professional. In naturally

occurring online narratives (such as blogs or websites), four out of twenty parents attributed delays in diagnosis to the paediatrician ignoring their complaints (Fleischmann, 2004). Conversely, in cases where the paediatrician performed an in-depth screening in response to parent concerns, an earlier AOD was reported (Adelman, 2010).

Evidence suggests that professional knowledge, awareness and experience of ASC may play a role in the age of recognition and referral. One study suggests that autism tends to be diagnosed earlier in areas with higher autism prevalence (Fountain et al, 2011). More recent birth cohorts tend to be diagnosed earlier (Adelman, 2010), which is a trend demonstrated across 12 studies (Daniels and Mandell, 2013). These findings could reflect improved professional experience and/or pro-diagnosis bias. Differences in AOD based on level of communication function has reduced over time (Fountain et al, 2011), which could be attributed to improved professional recognition of subtle signs of ASC.

Furthermore, findings consistently indicate that children with specialist professional involvement receive an earlier diagnosis. Those referred from specialist teams or early intervention programmes were diagnosed earlier in three studies (Daniels and Mandell, 2013), which is supported by findings that those referred from an 'early intervention program', rather than physician, school or parent were diagnosed earlier (Twyman et al, 2009). One study reports that children who were referred to a specialist were diagnosed 0.3 years earlier (Mandell et al, 2005). Whilst more specialist professional knowledge may lead to earlier diagnosis, child presentation factors may also contribute: those enrolled on programs are likely to have more 'obvious' ASC characteristics.

There are also risk factors pertaining to later diagnosis in relation to professional involvement. Evidence suggests that a change of paediatrician is associated with later diagnosis (Adelman, 2010; Daniels and Mandell, 2013). Having a higher number of professionals involved is likely to result in later

AOD (Daniels and Mandell, 2013), with one study reporting that children with four or more professionals involved received a diagnosis 0.5 years later (Mandell et al, 2005).

#### *2.3.4 Limitations of existing research*

Existing research seeking to explain differences in AOD has some serious limitations. Firstly, the inherently positivist epistemological and methodological assumptions result in a tendency to identify variables associated with earlier or later diagnosis. As a result, there is no overarching explanation of the complex factors and mechanisms to explain the reasons for later diagnoses in individual cases. The mixed and sometimes contradictory findings suggest that AOD cannot be explained using a simple causal model. From the literature reviewed, I conclude that complex combinations of these interacting factors are likely to influence AOD in individual cases.

Furthermore, this positivist stance has merely identified risk factors and associations in statistical terms, rather than understanding the complexity of causal mechanisms or the perceptions of the people whom later diagnosis affects. The methods used in the existing research often rely on secondary data, involving the use of databases and population-based studies (for example: Rosenberg et al, 2011; Mandell et al, 2010). Whilst this is advantageous in that data are comprehensive and offer an understanding of factors that may be associated with AOD, they lack a differentiated 'real world research' perspective (Robson, 2011) and reduce the stories of real people and their sense-making, to statistics and probable 'factors'.

There is limited existing qualitative research seeking parental views and attributions regarding their child's AOD. In her doctoral thesis study, Barrie (2010) interviewed parents about their attributions about the AOD. Parents reported that factors influencing an earlier diagnosis were: their persistence,



a specific program or professional, physicians who highlighted the symptoms and characteristics of autism to them, and having another child with ASC. Conversely, parents reported that factors influencing later diagnoses were: physicians dismissing concerns, opinions of family and friends, waiting lists, and lack of knowledge and awareness of professionals and agencies (Barrie, 2010). This study is, however, limited by the arbitrary cut-off between 'early' and 'late' diagnosis groups (before and after 30 months). Furthermore, whilst the study does use qualitative data from the parents' perspective, it still lacks in-depth exploration of the complex inter-relating factors that may 'explain' later diagnosis in each case. This highlights a clear need for new qualitative research to explore complete individual stories, in order to begin to understand the complex patterns of inter-linked events preceding later diagnoses of ASC.

#### *2.3.5 Summary*

To conclude, existing knowledge is derived from a primarily positivist stance and identifies 'factors' associated with AOD, but there is very little explanatory research into the interaction of factors surrounding later diagnoses. Furthermore, this research corpus has conceptualised (seemingly arbitrary) cut-offs between 'early' and 'late' diagnoses between 18 months-7years: this review identified no research with CYP who are diagnosed later than this.

In summary, there are two dimensions to the current research that have previously been neglected: (i) research relating to CYP diagnosed during late-childhood or adolescence; and (ii) in-depth, qualitative analysis of the complex, interacting factors that may precede a later diagnosis from a parental perspective.

## **2.4 The impact on parents of receiving an ASC diagnosis**

As receiving a diagnosis of ASC is not an isolated ‘life event’, I begin with a brief acknowledgement of the everyday impact of parenting a child with ASC. I then outline existing research into parents’ experiences, which I have conceptualised chronologically, distinguishing between parents’ experiences before, during and after diagnosis, as is common throughout the literature (Braiden et al, 2010; McCaffrey, 2011; Mansell and Morris, 2004). The document, ‘Information for Parents’, (DCSF, 2010) likens the diagnostic process to setting out on a journey, which implies progression over time and indeed a destination. These time periods do not necessarily represent discrete stages for parents, with unclear boundaries and likely individual variation. Nonetheless, this temporal conceptualisation provides a useful framework and is particularly relevant to the current study’s narrative approach (discussed fully in Chapter 3). Finally, I briefly outline the sparse existing literature into the effect of the child’s AOD on parents’ experiences.

### *2.4.1 Everyday challenges of parenting a child with ASC*

Descriptive research has sought to establish the impact of raising a CYP with ASC on parents. The NAPC (2003) suggests that, whilst learning that their child has any serious condition can be devastating for parents, autism is particularly challenging due to its ‘hidden’ difficulties and lack of apparent explanation for unusual behaviour. Compared to parents of typically developing children and those with other developmental disorders, Vohra et al (2013) indicates poorer outcomes<sup>3</sup> for parents of CYP with ASC. In addition, higher levels of parent stress have been reported in ASC-parent groups than parents of typically developing children (meta-analysis of 10 studies; Hayes and Watson, 2013) and

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<sup>3</sup> Poorer outcomes include: accessing services, quality of care and family impact, including financial, employment and time-related burdens.

parents of CYP with other disabilities, such as Down’s Syndrome, cerebral palsy or learning difficulties (12 studies; Hayes and Watson, 2013). This is supported by McStay et al (2014), who reported significantly greater levels of parenting stress in a Dutch sample of parents of children with ASC (n=150) than parents with typically developing children (n=54).

Explanatory studies have sought to explore the reasons for these poorer outcomes and the increased stress experienced by parents of children with ASC. The Autism Parenting Stress Index, developed and validated by Silva and Schalock (2012), identified three key factors that influence parent stress (core social difficulties, challenging behaviour and physical issues). Similarly, Molina (2014) interviewed parents (n=3) about the ‘everyday realities of living with autism’ and used content analysis to identify five thematic clusters, which appear to have concurrent validity with other research (Table 3).

*Table 3: The everyday experiences of parenting a CYP with ASC*

<b>Molina’s (2014) thematic clusters</b>	<b>Concurrent findings</b>
1. Managing the CYP’s behaviour and educational needs	<ul style="list-style-type: none"> <li>• Rivard et al (2014) reported that the severity of autistic symptoms and adaptive behaviours predict parental stress.</li> <li>• McStay et al (2014) concluded that associated behavioural variables, namely child hyperactivity, significantly predicted parental stress (rather than ASC severity per se).</li> <li>• ‘Inappropriate and unpredictable behaviour’ was ranked as the top source of stress by parents children with ASC (Tehee et al, 2009).</li> <li>• ‘Dealing with challenging behaviours’ (including children’s responses to changes to routine, tantrums and obsessive and repetitive behaviours) was reported as a major ‘stressor’ for parents (Ludlow et al, 2011; Mason, 2012).</li> <li>• Higher parenting stress is associated with CYP (with ASC and) more severe emotional symptoms, conduct problems and hyperactivity/inattention (Huang et al, 2014).</li> <li>• Child physical symptoms of pain (higher incidence and severity in ASC population) are reported to significantly interact with child problem behaviour, which in turn predicts parenting stress (Walsh et al, 2013).</li> </ul>

2. The impact on parent's well-being	<ul style="list-style-type: none"> <li>• Parental self-efficacy, stress, and mental and physical health may all be negatively affected (Karst and Vaughan Van Hecke, 2012).</li> <li>• Parental fatigue is higher in mothers of CYP with ASC than those of typically developing children, and was closely related to other aspects of parent well-being including anxiety, depression and stress and reduced parenting efficacy and satisfaction (Giallo et al, 2013).</li> <li>• Parents of older adolescents and young adults with ASC (aged 15-21 years) have described feelings of isolation, exhaustion, grief and frustration as 'causes' of stress (Mason, 2012).</li> <li>• Desperation, depression, loss and loneliness (Ludlow et al, 2011) have also been suggested as 'causes' of stress, although these feelings could be considered the 'effects' of stress.</li> </ul>
3. The impact on the whole family	<ul style="list-style-type: none"> <li>• Parental relationship satisfaction may be reduced in families with a CYP with ASC (Karst and Vaughan Van Hecke, 2012; Mason, 2012).</li> <li>• Sibling relationships may also be negatively affected (Karst and Vaughan Van Hecke, 2012; Ludlow et al, 2011).</li> <li>• Raising a child with ASC can influence the wider family system, including resources, disruption, quality of life, and a sense of bearing both emotional and practical burdens (Karst and Vaughan Van Hecke, 2012; Ludlow et al, 2011; Molina, 2014).</li> <li>• Karst and Vaughan Van Hecke (2012) also note the reciprocal nature of the child's difficulties impacting the family, whose stress and diminished coping capacity may, in turn, exacerbate the child's presenting difficulties.</li> </ul>
4. Integration into mainstream society	<ul style="list-style-type: none"> <li>• Parents reported that dealing with judgements from others was worse than the behaviour itself, highlighting the cumulative effects of parental stressors (Ludlow et al, 2011).</li> <li>• Parents reported a lack of support from organisations (although some felt well-supported) and information about resources (Ludlow et al, 2011).</li> <li>• Parents described frustration with the lack of support (Mason, 2012).</li> </ul>
5. Management of the diagnostic process itself	<ul style="list-style-type: none"> <li>• Discussed throughout Sections 2.4.2 and 2.4.3.</li> </ul>

In summary, the literature reviewed indicates that raising a child with ASC has significant, and primarily detrimental effects on parents and family life, which I propose are likely to have transactional, reciprocal and cumulative effects. Whilst this is not the focus of the current research, it sets the scene for exploring parents' experiences of receiving diagnoses of ASC.

#### *2.4.2 Diagnostic experiences for parents*

I now explore research into parents' experiences before, during and after diagnosis. The diagnosis is considered to be a highly significant event for parents (Slator, 2012) and is often positioned as a key turning point or 'complicating action' in parents' naturally-occurring online narratives, although cognizance of the child's autism may also represent a 'key turning point' and usually occurs just before or just after diagnosis (Fleischmann, 2004).

Parents' pre-diagnostic experiences are diverse and the age and severity of parental concerns is varied (NAPC, 2003). Ryan and Salisbury (2012) suggest that parental concerns may be categorised into: (i) no concern, (ii) passive concerns (parents are unsure why they concerned and are not seeking professional help); and (iii) active concerns (parents actively seek explanations). Research also suggests that some parents were aware of differences from birth, whilst others had no concerns (Braiden et al, 2010). The pre-diagnostic period is likely to be experienced differently depending on the level of parental concern. Evidence suggests that parents who have expressed concerns report confusion and inability to make sense of their child's behaviours (Midence and O'Neill, 1999). Furthermore, mothers who actively sought explanations have reported feeling anxiety and frustration at this stage (McCaffrey, 2011). Conversely, if parents have not suspected a developmental/behavioural condition, NICE (2011) guidance suggests that they are more likely to experience distress in response to diagnosis.

One pertinent theme relating to parental experiences pre-diagnosis, is that of parental concerns being taken seriously. Parents may be given false reassurances (Mansell and Morris, 2004) and concerns may not be taken seriously (Barrie, 2010). This often results in parental dissatisfaction with the diagnostic process (Sansosti et al, 2012). For actively concerned parents, premature reassurance left them feeling isolated and alone (Ryan and Salisbury, 2012). Reciprocally, higher parental satisfaction with the

overall experience is linked to professionals accepting parents' first concerns (Braiden et al, 2010). Ryan and Salisbury (2012) highlight the important distinction between offering reassurance and dismissing concerns. One parent reported feeling 'let down' by primary school staff, who had attributed her daughter's difficulties (later diagnosed as autism) to behavioural difficulties (Glazzard and Overall, 2012). NICE (2011) guidance now states that all parental concerns should be taken seriously, although signs of improvements in practice are yet to be evidenced by research.

Research into parents' experiences during the diagnostic period itself suggests mixed findings, which indicate highly varied, individualised experiences. Some parents report overall positive experiences, relating to being listened to and receiving information (Braiden et al, 2010), whilst others report less satisfaction with the diagnostic process, indicating that it was a stressful time (Rose, 2011). Parents have reported increased stress, distress, frustration and insufficient advice (Keenan et al, 2010) as well as feeling overwhelmed by multiple professionals (Braiden et al, 2010).

Consistent with findings that the diagnostic process can take between 2-4 years (Rose, 2011; Siklos and Kerns, 2007; Howlin and Moore, 1997), the length of the diagnostic process influences parents' experiences. Although in one study, some parents believed the length of the diagnostic period to be 'reasonable', approximately half of parents did not think that the diagnostic process was completed in a timely manner (Keenan et al, 2010). Moreover, one parent in Glazzard and Overall's (2012) research reported that "the waiting time was far too long", and a contingent sense of feeling "left in limbo". Overall, parents who waited less than a year between first seeking help and confirmed diagnosis tended to be more satisfied than those who had waited more than 2 years (Howlin and Moore, 1997), although Rose (2011) reported no significant correlation between length of diagnostic process and parental satisfaction, suggesting that satisfaction is better predicted by the number of professionals seen and level of parental stress.

Parents' responses post-diagnosis seems to have two elements: (i) the emotion-focused reaction to the diagnosis itself; and (ii) the task-focused action planning which inevitably ensues, including the search for information and appropriate support (Mansell and Morris, 2004; McCaffrey, 2011).

Generally, it appears that delivery of the diagnosis constitutes a difficult time for parents (Braiden et al, 2010) and is acknowledged to be a time of "great emotional upheaval" (DCSF, 2010, p. 3). When parents were asked for feedback about the communication of the final diagnosis, their emotional reaction was a key theme in Abbott et al's findings (2012). Guidance documents acknowledge that parents may experience a variety of mixed emotions, ranging from shock to relief (NICE, 2011; DCSF, 2010) and there is well documented wide variation in parental reactions to the diagnosis between different families (Slator, 2012), and even within families (DCSF, 2010). Some parents in Glazzard and Overall's (2012) study (n=20) used the negative emotional language of 'complete shock', 'upset', 'traumatic', 'a cruel finality' and 'brutal', whilst others embraced the disorder and sought to celebrate their child's differences. Whilst parents commonly express a sense of relief upon diagnosis (Abbott et al, 2012; Fleischmann, 2004; Mansell and Morris, 2004; Midence and O'Neill, 1999; Molina, 2014), evidence also suggests that they may also experience a grief reaction similar to the loss or death of a loved one (using Kubler-Ross's model of grief: denial, anger, bargaining, depression and acceptance; Castle, 1998). Similarly, parental feelings of grief are also reported by Mason (2012) and parents may mourn the loss of the 'hoped for' child (Mansell and Morris, 2004). Feelings associated with grief (anger and guilt) are normalised by the DCSF (2010) guidance document for parents. Features of individual CYP may also influence parents' emotional reaction: greater autistic symptomology has been associated with reduced stress in relation to the diagnosis, and more positive attitudes towards diagnostic services and processes (Siklos and Kerns, 2007).

Further research indicates a lasting emotional impact for parents. Casey et al (2012) reported evidence that an approximately 20% subpopulation of parents (n=265) may experience post-traumatic stress symptoms following the diagnosis. Other research evidence also suggests that 78.7% of mothers (n=75) experience clinically significant depressive symptoms in the week following diagnosis and 37.3% experience persistent depressive symptoms at one-year follow-up (Taylor and Warren, 2012). One study found high levels of caregiver burden<sup>4</sup> in parents of CYP diagnosed with ASC within the previous six months (Stuart and McGrew, 2009). However, findings from the latter two studies cannot be directly attributed to the diagnosis itself, as opposed to the everyday impact of raising a child with ASC, especially since findings of depressive symptoms also correlated with child problem behaviours (Taylor and Warren, 2012) in line with research discussed in Section 2.4.1. Evidence suggests that, although parenting stress may decline over the time from parents' initial concerns, confirmation of the ASC diagnosis does not significantly change parenting stress in either direction (Osborne et al, 2008).

Other research suggests that parents begin a process of meaning-making (Thompson-Kroon, 2011), adjustment over time and a change in attitude toward diagnosis (Mansell and Morris, 2004). Sweeney Gray (2013) suggests that parents' (n=22) initial feelings of worry and frustration may change over time to include increased optimism and perceived coping. Similarly, Molina (2014) reports that, over time, parents felt more empowered, and that the diagnostic label supported them through mourning and into action. In one study, parents' naturally occurring internet narratives acknowledged the challenges of coping with a CYP with ASC and the mixed emotional responses to diagnosis, whilst concluding with the positive themes of empowerment, optimism, success and celebrating progress (Fleischmann, 2004). Similarly, Slaton (2012) interviewed parents across two time points and found that new themes developed over time, 'self-belief', 'understanding', 'coping strategies', and 'optimism'. These narrative

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<sup>4</sup> Caregiver burden was characterised by: caregiver strain, the impact on the family, and perceived implications of having a child with a disability.



studies suggest that, over time, parents may re-create alternative, more positive narratives about their experiences. Slator (2012) concluded from her literature review that psycho-educational programmes for parents may assist this process.

Existing literature is heavily saturated with studies into post-diagnostic support for parents, including seeking information and accessing services, which is beyond the remit of this review. To give a brief outline, one early study reported that post-diagnostic support is perceived by parents as poor (Howlin and Moore, 1997): a finding, which despite expected improvements to services over time, has been replicated in recent research with 77% of parents reporting insufficient advice given at the time of diagnosis (Keenan et al, 2010). However, perceptions of support, access to services and quality of advice/information tend to vary between parents (Braiden et al, 2010; Boorn, 2010).

#### *2.4.3 Age of diagnosis in relation to impact*

Remarkably, despite the overwhelming interest in early diagnosis (discussed in Chapter 1), there is very limited research into how the CYP's AOD may affect parents' experiences before, during and after the diagnosis. Indeed, AOD is not often reported in this research corpus.

One large scale UK parent survey (n=1,300) reported that overall parent satisfaction was significantly correlated with AOD: parents of CYP who were diagnosed before the age of 5 were more likely to be satisfied (according to Likert scale data) than parents of those diagnosed later (Howlin and Moore, 1997). These findings demonstrated two reciprocal trends: firstly, the percentage of parents reporting to be 'very' or 'quite' satisfied was incrementally lower when the CYP's AOD was incrementally older; secondly, the percentage of parents reporting to be 'not satisfied' was incrementally higher when the CYP's AOD was incrementally younger (age brackets: <2 years, 2-5years, 5-10 years, 10-15 years, 15-

20 years; 20-40 years). One strength of this study is its inclusion of CYP (and even adults) in older age groups than most studies. This study is now almost 20 years old and these findings have not been replicated recently on such a large scale. One recent, smaller-scale study supported this, in reporting that families (n=16) who received a later diagnosis were significantly less satisfied with the diagnostic process overall, as indicated on a numeric scale in a semi-structured interview (Sansosti et al, 2012). This study, however, only included children diagnosed between 2-7 years. Another study contradicted these findings, suggesting that parent satisfaction (n=59) did not correlate with the child's AOD (Rose, 2011).

Fundamentally, the impact of an ASC diagnosis on parents is far more complex than can be reflected in quantitative measures of 'satisfaction' with the diagnostic process. One study, by Sweeney Gray (2013), sought to measure the impact of the child's AOD on parents (n=22) using the 'Family Impact of Childhood Disability Scale' (comprised of positive and negative scores), but found no correlation with AOD. Using the Parenting Stress Index (PSI), Sweeney Gray (2013) did find an overall positive correlation between parenting stress and the CYP's AOD, indicating that later diagnoses may be associated with higher levels of parenting stress. However, out of the three sub-scales on the PSI, only 'difficult child' and 'child-parent dysfunctional interaction' significantly correlated with AOD, whilst the third sub-scale, 'parent distress', did not correlate with AOD. Again, this study only included children diagnosed between 1-7 years and further highlights the gap in research with parents of CYP diagnosed aged 7 years and older.

Interestingly, Osborne et al (2008) suggest that it may not be the child's AOD that most impacts on parents, but rather the timescales between parents first noticing concerns and receiving the diagnosis. Unexpectedly, shorter timescales between noticing concerns and receiving the diagnosis were associated with higher levels of parenting stress, whilst longer timescales were associated with lower

levels of parenting stress. Due to the controversial implications regarding timely diagnosis and parental well-being, the authors express that this finding needs to be interpreted with caution. They offer the explanation that parents who say they want an early and speedy diagnosis are actually inferring that they want support, reassurance and access to services, and suggest parents should not have to wait for diagnosis. Despite this being recognised in guidance documents (NAPC, 2003; DCSF, 2010), it seems parental perceptions do not reflect evidence of this in practice. Parenting stress, however, is again only one aspect of the emotional impact of the diagnosis on parents and should not be assumed to be synonymous with the overall impact on parents. Osborne et al (2008) emphasise the need for further investigation.

#### *2.4.4 Summary*

Concluding this section of the literature review, it seems that a complex set of factors may influence parents' experience before, during and after diagnosis. Overall, existing literature into the impact of ASC diagnosis on parents has neglected to explore: (i) in-depth, qualitative and holistic analyses of individual parents' experiences across time, including their experiences before, during and after diagnosis; and (ii) how this may be affected by the child's AOD, particularly when the CYP is diagnosed considerably later (i.e. 7 years and older).

## **2.5 Conclusion**

The rationale for the current study arises from curiosity about the conflict between research suggesting that ASC *can* reliably be diagnosed as early as 2 or 3 years, and real-world practice, in which some CYP (and adults) are diagnosed later than this. I am curious about the reasons for later diagnosis,

in the context of so much existing research focusing on early diagnosis and intervention. This has led me to question the ontological status of autism: is it an essential 'thing' that has simply been missed in cases of later diagnosis, or does an interactionist perspective (biopsychosocial model) offer an explanation for later diagnosis, in which some children (and adults) may slide between sub-clinical and clinical presentation (APA, 2013; Appendix 1; Table 1) at different life stages, dependent on contextual factors? Furthermore, given the literature's emphasis on the benefits of early diagnosis and early intervention (despite tentative evidence), I am curious about the impact of later diagnosis on CYP, their parents and their families.

In this literature review I sought to outline existing research into the possible reasons for later diagnosis and to understand the impact of ASC diagnoses on parents. Firstly, I conclude that existing research has focused on identifying factors, such as demographic factors, child presentation, parental concerns and professional factors, which may be associated with AOD. Findings are mixed, indicating that there is no simple causal mechanism or linear model of risk factors for later diagnosis: I judge that explanations for later diagnoses are complex and varied between individual cases. This calls for further in-depth research to explore individual cases, in order to understand the interplay of these complex, interacting factors preceding later diagnoses and how they are interpreted by the people affected (in the current study, parents). The current study aims to illuminate an understanding of the complex, and often contradictory, findings of the positivist studies to date.

Secondly, I conclude from existing research that raising a child with ASC is recognised to be highly challenging and the diagnostic period may be particularly significant, although highly varied between parents. There is sparse existing research exploring the impact of the diagnosis on parents in relation to the CYP's AOD, thus highlighting another gap in existing literature.

The 'scoping' purpose of this review enabled me to identify theoretical and empirical gaps as follows: (i) a lack of research focusing on children who are diagnosed in late childhood-adolescence; (ii) a need for research taking an interactionist view to explore individual cases to understand the complex interacting factors contributing to later diagnoses; and (iii) a need for research to explore the impact of later diagnoses on parents. The current study aims to address these gaps: the methodological decisions in undertaking this original research are discussed throughout Chapter Three.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Chapter overview**

Arising from the conclusions of the literature review and explicated rationale for the current study, this chapter offers a detailed description of the current study's methodology. I firstly outline the aims and research questions, before explaining how my social constructionist epistemology shaped my rationale for a narrative design, with narrative interviews as the method. I outline participant recruitment procedures and introduce the participants of the current study, alongside assurance of ethical research practice. My strategy for data analysis, including both constructive and deconstructive practices, is transparently described in relation to each research question. Finally, I evaluate my efforts to achieve high quality research, in terms of trustworthiness and dependability (alternatives to validity and reliability).

### **3.2 Aims and research questions**

Having identified gaps in existing literature, the current study aims to achieve an in-depth exploration of parents' narratives of their CYP receiving a 'later' diagnosis of ASC. The explanatory aim is to understand the factors contributing to later diagnosis of ASC from the parental perspective. The descriptive aim is to illuminate parents' evaluations of their experiences and to understand the impact of the (later) timing of the diagnosis.

The two research questions of the current study are:

1. How do parents' narratives illuminate an understanding of the reasons for later diagnoses of ASC?
2. How do parents evaluate the impact of the (later) timing of an ASC diagnosis?

### 3.3 Philosophical underpinnings

All research is fundamentally underpinned by philosophical assumptions about the nature of reality ('ontology'; Bryman, 2012), and about the nature of knowledge, including how it can be acquired and communicated ('epistemology'; Cohen et al, 2007). Traditionally, early psychology sought to explain social phenomena in terms of entities (such as personality traits and internal mental states) and took the essentialist view that people's 'essence' can be objectively discovered (Burr, 2003). In arguing against the popular objectivist approaches of the time, Bruner (1990) argued for interpretative approaches to understand human cognition: how humans *construct meaning*. This is based on the social constructionist assumption that meanings do not exist in their own right: rather, meanings are created and interpreted by humans in social contexts (Robson, 2011).

The current study's narrative methodology has been shaped by social constructionist assumptions. From this perspective, I consider that knowledge is created and sustained by the shared activity of language (Gergen, 1985) and position 'narratives' as a by-product of social interchange (Gergen and Gergen, 1984). I consider that versions of reality are constructed through social action and language (Gergen, 1985), and I adopt the view that "narrative is not an objective reconstruction of life – it is a rendition of how life is perceived" (Webster and Mertova, 2007, p. 3). My social constructionist stance also acknowledges the historical and cultural specificity of narratives (Gergen, 1985): narratives construct versions of reality, which are dependent on the time and context in which they are created. I adopt Clandinin and Connelly's (2000, p. xxvi) view that narratives are not fixed and may change over time: "people live stories, and in the telling of these stories, reaffirm them, modify them, and create new ones".

Within narrative research, knowledge is often assumed to be co-constructed: "knowledge is therefore seen not as something that a person has or doesn't have, but as something that people do together"

(Burr, 2003, p 9). It can be argued that all narratives are fundamentally co-constructed (Salmon and Reissman, 2013), and that the participant and researcher are seen as two active participants, who jointly construct meaning throughout the research process (Reissman, 2008). It is deemed good practice for researchers to reflect upon their influences on the narratives generated, analysed and interpreted (Salmon and Reissman, 2013): ‘reflexivity’ (Section 3.6.4).

Social constructionism assumes an interest in the context in which versions of reality are created (in this case narratives). I have acknowledged the research context in Section 3.8.2, but have focused on the content and structure of participants’ narratives, rather than the social interactional aspects (Mishler, 1995). I acknowledge my influences on the narratives generated, analysed and interpreted (Salmon and Reissman, 2013), whilst privileging the meanings made by participants (Emerson and Frosh, 2009) and maintaining the foreground on participants’ voices and perspectives (Aguinaldo, 2007).

### **3.4 Research methodology: Narrative inquiry**

Having clarified my social constructionist stance, I now discuss the contingent methodological implications for this study. I explore definitions of ‘narrative’ in research contexts and provide a rationale for this approach in relation to the current study’s research questions.

#### *3.4.1 Narrative: Definitions and key features*

‘Narratives’ are considered to be a fundamental part of our everyday lives: human experience is “the stories people live” (Clandinin and Connelly, 2000, p. xxvi). Narrative theory postulates that humans



seek to make sense of the world through creating and sharing stories (Murray, 2003) and narrating our everyday lives to each other, such as recalling memorable events, describing our relationships or recounting our experiences (Gergen, 2000). Narrative is considered to be the organising principle for humans to impose structure on their experiences in order to make meaning from them (Sarbin, 1986); human experiences and narrative are considered inextricably linked (Webster and Mertova, 2007). Narrative research, therefore, does not require any unusual kind of performance from participants: it simply provides a time and context for participants to select and reflect upon events in their lives relevant to the research topic: “narrative inquiry is stories lived and told” (Clandinin and Connelly, 2000, p. 20).

The term ‘narrative’ is often used simply to refer to ‘a story’ (Sarbin, 1986), characterised by key story features: a representation of events, experiences and emotions, including the classic beginning-middle-end structure, characters and a plot (Reissman, 2008). I have adopted a broad, all-encompassing definition of ‘narrative’, to include all types of storied language, including both complete, overarching stories and embedded narrative segments (Reissman, 2008). Gergen (1997) usefully conceptualises that a series of ‘micro-narratives’ may be nested within a larger, overarching ‘macro-narrative’ (i.e. stories within a story). Furthermore, I embrace Polkinghorne’s (1988) conceptualisations of narrative, as both: (i) a *product* (a complete story); and (ii) a *process* of making a story (Polkinghorne, 1988).

#### *3.4.2 Rationale for narrative methodology*

Narrative methodology is reported to have gained an increasing profile in social research over the last three decades (Squire et al, 2013) and its proponents argue that it is the best way to understand human experience (Clandinin and Connelly, 2000).

Narrative research can be distinguished from other qualitative approaches by three key characteristics: (i) time; (ii) meaning; and (iii) context (Elliott, 2005). Firstly, time is an essential aspect of any narrative, both in terms of chronology (the sequencing of events) and temporality (the assumed unilinear progression of past, present and future; Polkinghorne, 1995). Secondly, narratives serve the fundamental function of making meaning from events (Crossley, 2010). By positioning narratives as the “organised interpretation of a sequence of events” (Murray, 2003, p.113), they give meaning to events in relation to the story’s conclusion or ‘plot’ (Elliott, 2005). Thirdly, all narratives are produced within a specific context for a specific audience (Elliott, 2005), although narrative researchers vary in the emphasis they place on contextual factors.

The function of narratives can be divided broadly into two main types: ‘event-centred’ and ‘experience-centred’, a conceptual distinction that has been maintained throughout the development of narrative research literature (Table 4).

*Table 4: Comparison of authors’ explanations of the functions of narrative*

Author	Function of Narrative	
	Event-centred Narrative (Research Question One)	Experience-centred Narrative (Research Question Two)
Labov (1972)	<b>Referential clauses</b> give a straightforward report of what happened (i.e. events-based)	<b>Evaluative clauses</b> communicate the meaning of the narrative for the speaker and convey their level of personal involvement (i.e. meaning-based)
Polkinghorne (1988)	<b>Explanatory purpose</b> of narrative research – aims to provide a narrative explanation of <i>why</i> something (that involves human action) has happened	<b>Descriptive purpose</b> of narrative research – aims to describe interpretations of the meaning and significance of events
Squire et al (2013)	<b>Event-centred approach</b> focuses on recounting particular events that happened to the narrator	<b>Experience-centred approach</b> focuses on the narrator’s thoughts and feelings about the events

Narrative methodology simultaneously permits exploration of event narratives and experience narratives (Squire et al, 2013; Table 4) and is therefore ideally suited to address each research question of the current study. Research Question One ('RQ1' hereafter) seeks to *explain* (Polkinghorne, 1988; Table 4) the reasons for later diagnosis of ASC by understanding parents' perceptions of the connectedness of events preceding the diagnosis. This is firmly embedded within narrative theory, which suggests humans seek to understand life events by establishing coherent connections between them (Gergen and Gergen, 1984). In this *referential* (Labov, 1972; Table 4) and *event-centred* approach (Squire et al, 2013; Table 4), the perceived key events can be sequentially and chronologically organised with a beginning, middle and end (Elliott, 2005). In addition, the significance of each event can be understood in relation to the whole story or 'plot' (Elliott, 2005), leading to an explanatory story. This 'narrative configuration' is unique to narrative research (Cortazzi, 1993; Polkinghorne, 1995). Narrative inquiry offers the unique benefit of capturing the richness and complexity of 'the whole story'; through their narrative structure, stories can illuminate real life situations (Webster and Mertova, 2007). Research Question Two ('RQ2' hereafter) *describes* (Polkinghorne, 1988; Table 4) and *evaluates* (Labov, 1972; Table 4) participants' *experience-centred* narratives (Squire et al, 2013; Table 4) about later AOD.

### **3.5 Consideration of alternative methodologies**

Having presented a clear rationale for selecting narrative methodology, Table 5 explains my rationale for discounting other similar research methodologies.

Table 5: Consideration of alternative methodologies

Methodology		Opportunities	Limitations/Conclusion
Phenomenological approaches		Phenomenological approaches could usefully address RQ2 in portraying individuals' first-hand experiences (Giorgi and Giorgi, 2003) of the phenomenon of 'later diagnoses of ASC' and in understanding parents' experiences of this phenomenon (Smith, Flowers and Larkin, 2013).	<p>The essentialist perspective of phenomenological research does not suit my social constructionist assumptions (Section 3.3). Phenomenological researchers are concerned with understanding 'lived experience' and posit that experiences can be understood as they have 'actually happened' (Giorgi and Giorgi, 2003). The approach assumes a realist position and talks about accessing the 'essence' of participants' experience (Smith, Flowers and Larkin, 2013). Narrative approaches are more flexible, acknowledging that individuals' constructions of events may change over time and may vary depending on the story-telling context.</p> <p>Furthermore, the methods of generating and analysing data in phenomenological research do not lend themselves to addressing RQ1. Phenomenological approaches reduce data to themes to describe how several people experience a shared phenomenon (Creswell, 2007), whilst narrative approaches seek to keep individual stories intact (Reissman, 2008), thus allowing for the production of individual explanatory stories. Narrative inquiry has the benefit of capturing each participant's whole story and the links between events, rather than just exploring phenomena at certain points (Webster and Mertova, 2007).</p>
Discourse methods	analytic	This approach is better suited to my social constructionist epistemology. The approach applies a more profoundly social constructionist approach and seeks to explore how humans actively construct the social world through language (Burr, 2003).	Discourse analytic methods tend to be more action-oriented, including two branches to the approach: (i) discursive psychology, which posits that language is performative and asks 'what are participants <i>doing</i> with their talk?' and (ii) Foucauldian discourse analysis, which is concerned with how language and power shapes our social and psychological worlds and asks 'how does discourse <i>construct</i> subjects and objects?' (Willig, 2003). My research questions lend themselves to event-centred and experience-centred aspects of participants' stories (Squire et al, 2013). Although this overlaps with the interests of some narrative researchers, who emphasise the social and interactional aspects of narrative, this is not the primary focus of the current research.

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'Grounded theory' methodology	This could serve the explanatory purpose of RQ1, by systematically gathering data and analyse these inductively, to develop concepts to categorise and explain the data (Charmaz, 2003). Theoretical sampling to check and refine conceptual categories, could achieve the goal of developing a theory about later diagnosis of ASC (Charmaz, 2003).	It is not an aim of the current study to generalise across cases; instead, narrative approaches are case-centred and researchers seek to preserve the sequential narrative of each case (Reissman, 2008). Narrative research is unique in preserving the sequences of events and preserving the individual story, rather than segmenting data to code it thematically (Reissman, 2008). Narrative researchers, therefore, willingly sacrifice generic explanations, in favour of comprehensiveness (Elliott, 2005).
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### **3.6 Method: Narrative interviews**

I now explicate my rationale for choosing narrative interviews as the research method. I describe how the interview schedule was developed and outline practical arrangements for data collection (or 'data construction'; Elliott, 2005), including analysis and application of feedback from the field-testing of the interview schedule. I critically reflect on my role as researcher throughout the process of designing, conducting and reporting this research.

#### *3.6.1 Rationale for narrative interviews*

Narratives, as a product or story, can take many forms: personal accounts, autobiography, family stories, oral histories, journals and letters (Gergen, 2000). Czarniawska (2004) describes three main ways to 'collect' stories: (i) recording spontaneous stories from ethnographic research; (ii) eliciting stories, such as through research interviews; or (iii) asking for 'existing' stories, such as written accounts. I rejected ethnographic approaches as there were no obvious contexts for the generation of appropriate stories, as well as the challenging practicalities, such as longitudinal time commitment and prolonged intrusion in participants' lives. It was judged unlikely that existing written accounts (such as parent diaries) about the research topic would already exist in sufficient detail to address the research questions. Interviews are reported to be the primary source for generating narratives (Murray, 2003) and this method was adopted for the current study.

In positioning narratives as stories of human experience, it follows that interviews are considered to be a 'narrative occasion' (Reissman, 2008), in which stories are generated orally between researcher and participant. Narrative interviews provide a platform for the generation of detailed stories, unlike traditional interview practices, which may be restricted to brief, rigid and formulaic question-answer interaction (Reissman, 2008).

### 3.6.2 Development of the interview guide

Despite narrative interviews being considered the main method for generating narratives (Murray, 2003), the literature lacks comprehensive practical guidelines. Nonetheless, a ‘recipe’ approach would be unlikely to prove universally appropriate: successful approaches in one research context are unlikely to be transferable to others (Czarniawska, 2004). Instead, the narrative interview schedule should be contingent on the research purpose and questions, anticipated participant characteristics and the type of narrative interview.

Narrative research has been described as a ‘family of approaches’ (Robson, 2011), and Creswell (2007; Table 6) describes five types of narrative study, with indistinct boundaries: my research has elements of biographical and life history narratives (in generating narratives spanning the CYP’s entire life), but also suits an oral history approach (exploring links between events preceding later diagnoses of ASC).

*Table 6: Types of Narrative study (Creswell, 2007)*

Type of Narrative	Description
Biographical narratives	The researcher collects another person’s life experiences.
Autobiographical narratives	The participants write and research their own stories.
Life history narratives	These narratives span an individual’s entire life.
Personal experience stories	These narratives refer to a narrative study of an individual’s experiences (including single or multiple episodes).
Oral history narratives	These narratives refer to personal reflections on the causes and effects of events.

Given the timespan of interest (the CYP’s entire life), I drew upon Elliott’s (2005) recommendation to use a life history grid. She suggests that arranging key events chronologically is a helpful way to position key events in relation to each other. McAdams’ (1993) personal interview schedule provides a similar, but even more structured narrative interview agenda. The main benefit of McAdams’ (1993; Table 7) schedule is the opportunities it affords to generate both event-based and experience-based

narratives. Firstly, identifying ‘chapters’ and ‘key events’ enable the generation of event-driven explanations (narratives) of key moments (and the links between them) preceding the later diagnosis of ASC, in relation to RQ1. Secondly, asking value-laden questions about participants’ experiences (including peak and nadir moments) affords opportunity for parents to reflect on their interpretations and evaluations of events, in relation to RQ2.

To structure my interviews, I adapted McAdams’ (1993) interview protocol, which was originally intended for use within auto/biographical research (Crossley, 2010). The full interview guide is included as Appendix 3 and Table 7 presents a brief outline. This interview structure is not intended for use as a standardised protocol. Mishler (1986a) rejects the idea that research interviews should be modelled on the experimental approach, striving for standardisation and replicability. He redefines interviews as meaningful ‘speech events’ between researcher and participant. Variation between interviews is indeed advantageous because meanings can be clarified and negotiated (Mishler, 1986a). The interview design (Table 7) is, therefore, used as a *guide*, rather than a *schedule*, to encourage informal ‘conversation’ and development of narratives (Reissman, 2008).

*Table 7: Interview Guide, adapted from McAdams’ (1993) personal narrative interview*

<b>McAdams (1993) personal narrative interview schedule</b>	<b>Adaptations for the current study</b>	<b>Rationale</b>
1. Life chapters	<b>1. Life chapters</b> <i>Ask participants to imagine their child’s life as a book (or film) and divide it up into chapters (perhaps between 2 and 8). Then, ask participants to recall an important memory from each chapter.</i>	This was considered useful in structuring the elicitation of key events, and allows participants to decide the time span of each chapter. This also requires participants to select and evaluate key events and happenings from each chapter that they believe to be relevant to the story’s plot (later diagnosis of ASC).
2. Key events: • Peak experience (a high point or best moment)	<b>2. Key events:</b> • Peak experience (a high point or best moment) • Nadir experience (a low point or worst moment)	The value-laden wording invites parents to evaluate the key events and comment on why these memories are the best/worst moments, which is particularly useful in relation to Research Question Two.



<ul style="list-style-type: none"> <li>• Nadir experience (a low point or worst moment)</li> <li>• Turning point</li> <li>• Earliest memory</li> <li>• An important childhood memory</li> <li>• An important adolescent memory</li> <li>• An important adult memory</li> <li>• Other important memory</li> </ul>	<ul style="list-style-type: none"> <li>• Turning point</li> </ul> <p><i>Using prompt cards, ask participants to identify the above along the timeline.</i></p>	<p>These three key events were selected in anticipation that this would add sufficient detail to the memories recalled so far. The other memory questions (earliest memory, childhood, adolescent etc) were deemed less relevant, as they are more suited to personal life history interviews; they were therefore omitted.</p>
3. Significant people	<b>3. Significant people</b> <i>Using prompt cards, ask participants to identify 2-3 people (characters) that have had a significant impact on their child's life.</i>	<p>This aspect also has an in-built evaluative aspect, in asking participants to select and discuss key people that have influenced the overall plot (either progressively or regressively).</p>
4. Future scripts	<b>4. Future scripts</b> <i>Using prompt cards, invite participants to describe their predicted short, medium and long term future</i>	<p>Participants were tentatively invited to describe future chapters, in order to respect the possibility that they may not have thought about the future, nor wish to do so, particularly if they believe it will be negative or distressing to do so.</p>
5. Stresses and problems	-	<p>This was omitted, as I did not want to overly focus on the negative and cause distress to participants. I anticipated that any relevant stresses and problems would emerge throughout parents' narratives, without having to ask explicitly.</p>
6. Personal ideology	-	<p>Enquiring about parents' own personal ideology was also omitted as I anticipated that this could lead parents to reflect upon their own identities, which is not the focus of the current research. The life theme (see below) was judged to be more relevant.</p>
7. Life theme	<b>5. Life theme</b> <i>Ask participants to summarise the whole experience. Invite them to think of a theme or a title for their story.</i>	<p>I considered this to be a useful way of asking participants to reflect upon the meanings of the narratives created throughout the interview. It also neatly signaled the ending of the interview.</p>

### *3.6.3 Field-testing and implementation of the interview guide*

As Horsdal (2012) recommends, I informally field-tested the interview schedule on someone known to me, who had a son diagnosed with autism at the age of 15. The main purpose was for me to become familiar with the role of the interviewer and to confirm the practicality of the interview guide: I found that McAdams' chapters approach worked well to structure the narrative. I found that simplifying the language of 'peak' and 'nadir' experiences to 'best moment' and 'worst moment' was helpful, and planned to make this adaptation in the interviews.

Based on the narrative literature, I anticipated interviews to each last approximately 90 minutes (Elliott, 2005), but allowed 1-2 hours. This expectation was clarified with participants (Appendix 4), which also helped them to gauge how much detail to provide. In the end, both interviews lasted under 2 hours, within which the full Interview Guide was discussed, including a short comfort break. Although participants were invited to a second meeting (intended for additional interview time or mutual reflection), both participants declined. To respect participants' rights and maintain ethical integrity, I agreed with them that debriefing was sufficient within the first meeting.

During the interview, some researchers consider it sufficient to rely on contemporaneous handwritten notes (Horsdal, 2012), but I followed advice to audio-record my interviews, which is generally considered good practice (Elliott, 2005). This allowed me to focus on listening attentively during the interview and ask appropriate follow-up questions (Elliott, 2005; Appendix 3). Having audio-recorded interviews, which were later transcribed (Section 3.9), I was able to revisit aspects of interest and achieve deeper and more rigorous data analyses, facilitating greater persuasiveness in reported findings (Reissman, 2008). Although audio-recording interviews may alter participants' self-presentation, disclosure and censorship, upon balance, I judged that the advantages of audio-

recording outweighed this. In seeking to habituate to the presence of the recorder, I began the recording immediately after securing informed consent.

Reissman (2008) argues that, in order to generate quality narratives, a different interview 'climate' is needed, in which storytelling is allowed. In narrative interviews, the ratio of talk between participant and researcher is weighted more heavily toward the participant, requiring longer turns than is usual in everyday conversation (Reissman, 2008). According to the narrative assumption that storytelling is intrinsically human, Mishler (1986a, p. 69) argues that "it is apparently no more unusual for interviewees to respond to questions with narratives if they are given some room to speak". Hollway & Jefferson (2000), however, suggest that it can take time to build participants' confidence that the researcher is interested in their extended narratives. This emphasises the importance of rapport building and clarifying expectations (Elliott, 2005), which I planned for (Appendices 3 and 4) and sought to achieve (Section 3.8.1.1 and 3.8.1.2).

As the interviews drew to a close (i.e. when each section of the interview guide, Appendix 3, had been discussed), participants were debriefed, firstly by inviting them to tell me anything else that they felt was relevant or that they had not had chance to discuss. I then thanked them for their time and asked them "how was this interview experience for you?" and "how have you been left feeling?" This gave participants time to reflect upon their immediate emotional reactions to the interview experience, and I provided contact details for local support organisations, as well as my own and my supervisor's contact details, should they wish to seek further information or advice, in line with ethical considerations detailed in Section 3.7.

### 3.6.4 Reflexivity

I acknowledge my influence as researcher upon the co-construction of knowledge throughout the generation, analysis and interpretation of the narratives in the current study. This is often referred to as *reflexivity*, defined as “heightened awareness of the self, acting in the social world” (Elliott, 2005, p. 153) and serves to explicate the researcher’s role and perspective (Aguinaldo, 2007), which is considered good practice (Salmon and Reissman, 2013). Exercising reflexivity and ‘open-mindedness’ facilitates the unpacking of the researcher’s presuppositions, demanding that “we be conscious of how we come to our knowledge” and that “we be accountable for how and what we know” (Bruner, 1990, p. 30). This is important when evaluating the trustworthiness and dependability (validity and reliability) of the research (discussed in Section 3.10 and 6.3). Based on Elliott’s (2005) recommendation, I acknowledge the influence of my theoretical and autobiographical background on two levels: (i) my relationships with participants and the generation of narratives; and (ii) my interpretation and analysis of data.

Firstly, in Chapter One, I offered brief autobiographical details, although Elliott (2005) emphasises that this is not sufficient to claim reflexive awareness: explicit reflections on *how* this influenced the research are necessary. My prior professional experience as a teacher for ASC, and my current position as a Trainee EP within a Local Authority that values working closely with parents, have shaped my empathy towards the current study’s participants and my genuine interest in their stories. During the interviews, my primary aim was to demonstrate emotionally attentive and engaged listening (Reissman, 2008) and to be confidence-inspiring, attentive and responsive (Horsdal, 2012). Whilst participants were talking, I sought to signal my interest, both orally, by using ‘attention markers’, such as “mm hmm”, “right”, “okay” (Mishler, 1986b), and non-verbally, by nodding, making eye contact, using authentic empathic and interested facial expressions, and using hand gestures to invite participants to continue. I occasionally used general probes (Appendix 3) to elicit further information

or an evaluation, clarify meaning, or generate specific examples, which I acknowledge may have shaped participants' narratives. I discuss relevant contextual factors in each interview in Section 3.8.2.

Secondly, reflexivity illuminates the role of the researcher as narrator, in interpreting and 'restorying' participants' narratives (Elliot, 2005). I have used my own active, first-person voice throughout the report, to remind the reader of my influence. I acknowledge that my interpretations and 'readings' of each interview were shaped by my prior professional experience. In my current position as Trainee EP, I have had frequent opportunities to work alongside my supervisor, the Specialist Senior EP for ASC, who chairs the ASC diagnostic panel and takes a strategic lead in assessing and diagnosing ASC. Through this experience, and other arising EP casework, I have developed a theoretical interest in how ASC and other conditions are conceptualised, and the interaction of biological, social and psychological factors (see: Frith, 2003; Karim et al, 2012; Yates and Le Couteur, 2013; Vacanti-Shova, 2012; Cicchetti and Toth, 2009; Brody 2014; Engel, 1977; Bolton, 2014). Related to this and situated within my social constructionist assumptions, I have also developed an interest in the professional skills of hypothesis-testing and formulation. This has influenced my interpretations of participants' narratives and has shaped the focus of my analysis. Furthermore, my daily practice as a Trainee EP is shaped by the introduction of the latest Special Educational Needs and Disability Code of Practice (DFE/DOH, 2015), with its emphasis on multi-agency working, and this has also influenced my interest in different professional roles relevant to participants' stories in the current study. Findings are also interpreted in light of my commitment to improving services and experiences for CYP and their families.

Finally, my prior knowledge gained from conducting the literature review has also shaped my interpretations of data generated in the current study. Analysis was therefore both deductive (searching for aspects relevant to existing literature) and inductive (adding new insights that have not previously been considered in the literature).

### 3.7 Ethical considerations

Ethical issues relevant to this research were considered in relation to the British Psychological Society's Code of Human Research Ethics (BPS, 2010) and the British Educational Research Association's Ethical Guidelines for Educational Research (BERA, 2011). Prior to the commencement of participant recruitment and data collection, ethical approval was sought and gained from the University of Birmingham's Research Ethics Committee: full details are provided in Appendix 5. The salient ethical issues of the current study and steps taken to address them are summarised in Table 8.

*Table 8: Steps taken to address salient ethical issues in the current study*

<b>Ethical Issue</b>	<b>Steps Taken to Address the Issue</b>
Identifying, approaching and recruiting participants	<ul style="list-style-type: none"> <li>• Participants were contacted initially by the Chair of the Autism diagnostic panel, inviting opt-in consent.</li> <li>• Recruitment is explained further in Section 3.8.1 and Appendix 5.</li> </ul>
Confidentiality	<ul style="list-style-type: none"> <li>• Pseudonyms were used in the transcripts and report.</li> <li>• I exercised transparency in the level of confidentiality that was offered (e.g. explaining to participants that specific details may reveal their family's identity)</li> <li>• I clarified with participants their right to withdraw and right to withdraw their data.</li> <li>• I gave transparent information about the planned dissemination of the research (as recommended by Elliott, 2005), so participants were able to make informed decisions about participation.</li> </ul>
Right to withdraw, particularly in relation to certain details or comments	<ul style="list-style-type: none"> <li>• Participants' right to withdraw were explained on the participant information sheet (Appendix 4) and orally to ensure their understanding.</li> <li>• I gave transparent explanations to participants that specific details/comments could be deleted from the transcript but not from the audio recording.</li> <li>• Participants were given opportunities to exercise their right to withdraw during the interview or to withdraw their data for a period of up to seven days afterwards.</li> </ul>
Risk of emotional discomfort or distress for participants	<ul style="list-style-type: none"> <li>• Selection criteria exclude those who've received a diagnosis within the previous 6 months, in order to avoid recent and 'raw' emotions (Section 3.8, Table 9).</li> <li>• The literature suggests that narrating one's experiences can be therapeutic for research participants (Murray, 2003; Hollway and Jefferson, 2000). Furthermore, empathic narrative research can generate first-hand understandings of people and their experiences, which can lead to increased appreciation and sensitivity towards them (Gergen, 2000).</li> <li>• With my background and training in counselling and therapeutic</li> </ul>

	<p>skills, I was well-positioned to conduct the interview sensitively, with genuine empathic listening and attuned responding to parents' emotional needs.</p> <ul style="list-style-type: none"> <li>• In the event of a participant becoming emotionally distressed, I had planned to remind participants of their options to pause the interview at any point, choose not to discuss topics further or choose to fully withdraw from participation. Fortunately, this was not necessary.</li> <li>• Debriefing allowed participants time to reflect on their emotions during and after the interview (see interview guide, Appendix 3).</li> <li>• Participants were given information about where to seek advice, following the interview, should the need arise (see participant information sheet, Appendix 4).</li> </ul>
Respect for participants' narratives (their data)	<ul style="list-style-type: none"> <li>• The transcription, analysis, interpretation and reporting of narratives can also have an effect on participants (Elliott, 2005).</li> <li>• Horsdal (2012) suggests that a narrative should be considered as a 'gift' to the researcher, and treated with appropriate gratitude and respect.</li> <li>• I applied Sikes' (2010) 'acid test' of ethical respect, by asking: 'how would I feel if I was written about or depicted in this way?' in order to reduce the likelihood of representing participants in an unflattering, inaccurate or badly misinterpreted way.</li> </ul>

### 3.8 Participants

#### 3.8.1 Participant selection and recruitment

The narrative literature recommends first selecting a phenomenon (in this instance: the reasons for and experiences of later diagnosis of ASC) and then deciding upon the informants (Shedki, 2005). I considered working with CYP as informants to gain valuable insights into experiences of later diagnosis of ASC, but chose parents as more appropriate informants: my rationale is threefold. Firstly, parents are better positioned to narrate events throughout the child's *whole life* including infancy. Secondly, for ethical reasons, I decided to avoid lengthy, detailed interviews with the CYP about their diagnosis, as they may not have had prior opportunities to process and reflect upon it. Not only could this unnecessary distress, but could also limit opportunities to gather data relevant to RQ1. Finally, research suggests that CYP with ASC may have limited story-telling skills (Manolitsi and Botting, 2011), including recalling less sophisticated narratives of personal experience (Losh and Capps, 2003) and

producing less coherent narratives (Diehl et al, 2006). Specifically, research shows that CYP with ASC may use a restricted range of evaluative devices in their narratives (Capps et al, 1999) and demonstrate impairments in making causal connections across episodes of a story, which are thought to be linked to underlying difficulties with social and emotional understanding (Losh and Capps, 2003). One study suggests that young people aged 11-14 with ASC may produce shorter event narratives with fewer mental state references and evaluative devices than typically developing peers (King et al, 2013). It may be difficult, therefore, to generate coherent event-centred narratives (RQ1) and detailed experience-centred narratives (RQ2) from this population. Valuable accounts of CYP's own experiences could be generated using different methodology, but was deemed inappropriate to the current study.

Narrative inquiry often begins with the ethical negotiation into the data-gathering situation (Connelly and Clandinin, 1990). Participants were recruited from the Local Authority within which I was placed as a Trainee EP. In order to respectfully and ethically gain access to potential participants (and in line with the Data Protection Act, 1998), I arranged that my placement supervisor, the chairperson of the ASC diagnostic panel, would identify potential participants, who met my selection criteria (Table 9) and contact them via a letter (Appendix 6), which described the study, including a participant information sheet (Appendix 4, as recommended by Thomas, 2013), and invited parents to opt in by including my contact details. I included a return form and self-addressed envelope, which proved useful, as both participants used this method to contact me. Thomas (2013) cautioned that relying on opt-in consent can lead to biases, as only those who *want* to participate are recruited. In the current narrative study, however, willingness to participate is an advantage: participants are more likely to generate rich narratives relevant to the research topic.



Potential participants were initially identified by the selection criteria in Table 9. They were sorted into a random order using a 'Microsoft Excel' spreadsheet function. Recruitment letters were initially sent to the first five potential participants, in order to prevent over-recruitment. This produced a response rate of two participants, which was ideal for the current study: the narrative research literature recommends gathering data from one or two participants (Creswell, 2007).

*Table 9: Participant selection criteria and rationale*

<b>Selection Criteria</b>	<b>Rationale</b>
The child has received a diagnosis of an ASC (including Asperger's Syndrome)	This is the central phenomenon of the current study. Any type of diagnosis under the umbrella of 'ASC' was included.
The child was aged 12 or over at the time of diagnosis	In this study, I have defined 'later diagnosis' as over the age of 12 years. This is much later than existing definitions or 'cut-offs' used in the literature (Chapter 2), which distinguishes the current research. The age of 12 onwards was also chosen as this implies that CYP will not be currently experiencing a primary-secondary school transition.
The diagnosis was made at least 6 months prior to the time of recruitment	This criterion was primarily an ethical measure, preventing working with participants who may still have 'raw' emotions related to the diagnosis. These parents could also have a different agenda, perhaps seeking to ask the researcher questions about the diagnosis. This criterion also means that participants will have had more time to reflect upon the impact of the diagnosis and its timing, in relation to Research Question Two.
The parent has lived with their child all their life (excluding: Looked After Children and adoptive parents)	This is essential for the parent to be able to recall and narrative key events throughout the child's entire life.
The child may attend any kind of provision (mainstream school, special school, alternative provision etc)	There is no reason to limit the participant group based on these criteria: I wanted to keep the options open.
The child may have been referred through any professional route (e.g. Child and Adolescent Mental Health Services, Educational Psychologists, Paediatrician etc)	Again, there is no reason, in relation to the current study, to limit the participant group based on the referral route.
The child can be included if they have another diagnosis (e.g. Attention Deficit Hyperactivity Disorder)	Research shows that dual and/or misdiagnosis may be common in later diagnoses of ASC (Chapter 2). By limiting the research to those with a sole diagnosis of ASC, this may be omitting an important part of the narrative.

### *3.8.2 Contextual information about participants and the interviews*

In narrative research, inclusion of contextual information about the interviews is important for the reader to make their own subsequent interpretations of the researcher's analysis (Hollway and Jefferson, 2013), as well as judgements about the quality of research (Creswell, 2007; Section 3.10). Collecting descriptive background information about participants is recommended (Murray, 2003) and sometimes referred to as a 'pen portrait' in which the participant 'comes alive' for the reader (Hollway and Jefferson, 2013). In continuing to exercise reflexivity, I acknowledge contextual factors of the interviews (Mishler, 1986b), although the interactional aspects of the interview are not the focus of analysis (Mishler, 1995). I briefly introduce each participant, based on information they provided in during initial interview questions (Appendix 3), and reflect upon relevant contextual factors that may have shaped each interview.

#### *3.8.2.1 Introducing Maria and Kyle*

Maria<sup>5</sup> told the story of her son, Kyle, aged 14 at the time of the interview. He lives with his mother, father and younger brother, Charlie, aged nine, with whom he generally has a good relationship. Maria disclosed a family history of dyslexia on both sides of the family, including Kyle's parents, grandparents and great-grandparents, although Kyle does not have dyslexia. Charlie, Kyle's brother, has verbal dyspraxia and used sign-language to communicate until the age of five. Kyle was diagnosed with 'Autistic Spectrum Disorder' between the ages of 10-12 years. He also received a diagnosis of dyspraxia, which mainly manifests in his gross motor skills. Maria reported that when he was younger he showed "traits of ADHD" (Attention Deficit Hyperactivity Disorder), but she acknowledged the symptom overlap with ASC. Kyle attended a mainstream secondary school and, although he did not

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<sup>5</sup> All names have been changed.

have a Statement of Special Educational Needs<sup>6</sup> (DfES, 2001), he had additional support including special exam arrangements and regular progress meetings between his parents and the school staff to monitor his achievement and behaviour.

At the start of Maria's interview, she seemed enthusiastic and it was easy to build rapport. She seemed to respond positively and confidently to my invitation to "do most of the talking". I felt that the interview climate was relaxed, with a fairly even power balance: as a result, Maria seemed open and unguarded. She disclosed that she had participated in previous research interview, which focused on how raising a child with special needs affects parents. Maria's rehearsed narratives or previous 'themes' identified in that research interview may have led to demand characteristics in the current study, explaining her tendency to talk generally about her everyday experiences (Appendix 7). I also interpret that Maria's motivation for research participation was shaped by her desire to further reflect upon her own identity, make sense of events and to be 'heard', in a therapeutic context. Whilst trying to keep a balance between sensitive listening to Maria's thoughts and experiences and the research aims, I sought to keep the interview on course by gently steering the interview back to the mainline plot, for example by waiting for a natural pause and saying "sorry to cut you off, but just to move us on..."

### *3.8.2.2 Introducing Cathy and Jake*

Cathy narrated the story of her son, Jake, an only child. When Jake was approximately four, Cathy met her new husband (Jake's stepfather) and she described living "as a family" ever since. At the time of the interview, Jake was 17 years old, and had been diagnosed with Asperger's syndrome the previous

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<sup>6</sup> A 'Statement of Special Educational Needs' (DFES, 2001) refers to a legal document linked to the Education Act (1996), which details the educational needs and appropriate provision for a CYP in cases wherein they are unable to be met within the school's own resources. It is produced by the Local Authority following a statutory assessment of a CYP's educational needs (DFES, 2001). In the latest SEN Code of Practice (DFE/DOH, 2015) 'statements' have been replaced with 'Educational, Health and Care Plans (EHCPs)'.

year. Jake was diagnosed with Tourette's syndrome aged 6-8, as a result of tic-like behaviours or "habits" (blinking, facial twitches and ear flicking), but Cathy reported that this diagnosis has been questioned since the diagnosis of Asperger's syndrome, as the symptoms could be explained by the ASC. Jake attended mainstream primary and secondary schools, without a Statement of Special Educational Needs<sup>2</sup>, and is due to study Business Studies at college next year.

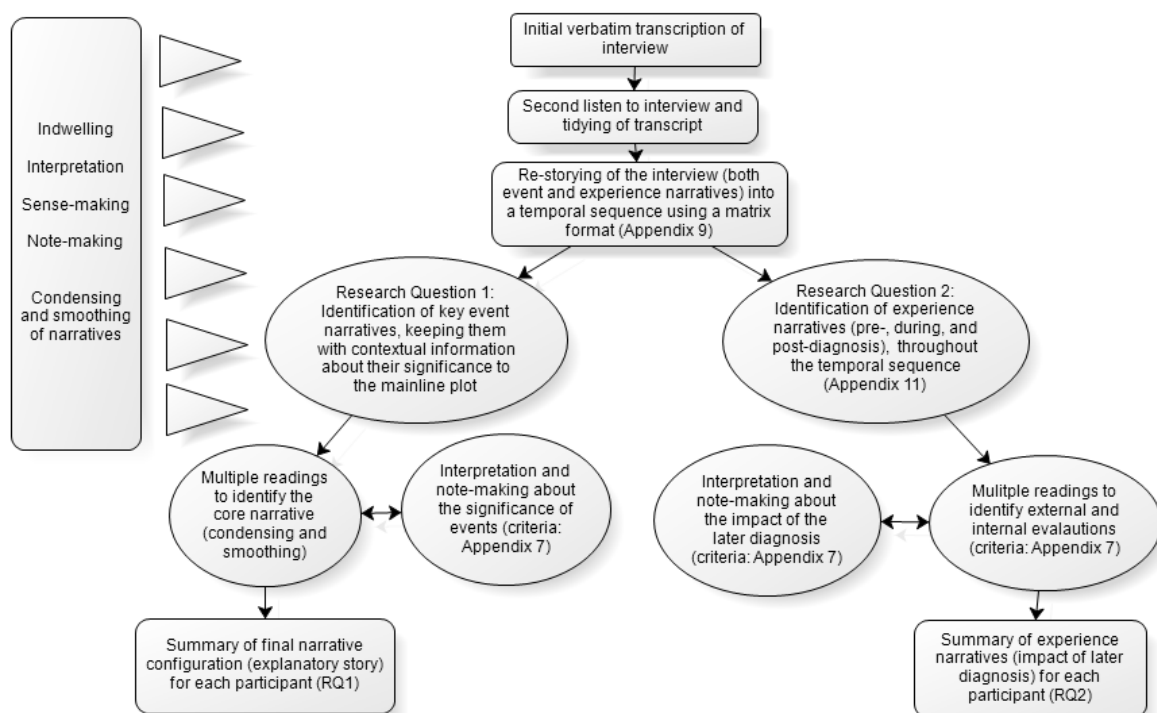
Initially, during Cathy's interview, she seemed nervous and repeatedly asked for clarification, seemingly keen to meet my research aims. As a result, I felt a heightened awareness of the power differential between us: despite my invitation for Cathy to "do most of the talking", she seemed unsure about what to say. At first, I sought to reduce the power imbalance by giving reassurance and creating an emotionally 'safe' interview context: I emphasised the importance and value of research seeking to understand parents' first-hand experiences and explained that I was interested in all aspects of Cathy's story of how Jake came to be diagnosed with ASC. I adopted an informal and light-hearted tone, which served to relax the interview atmosphere. For example, when Cathy found it difficult to think of 'chapter' titles, I sought to put her at ease by prompting her to use her own key words, such as "special baby".

During Cathy's interview, she explained that she wanted to participate because she was interested in the lack of "definite answers". Although she declined the offer of a second meeting to discuss the interview, Cathy did request a summary of the research, further highlighting her interest and personal search for improved understanding of the reasons for later diagnosis of ASC. Finally, Cathy described that Jake's diagnosis "only occurred last year", which may explain her sometimes lengthy pauses before she responded, her narratives being less well-rehearsed.

### 3.9 Analysis and interpretation of data

Despite the reported increasing popularity of narrative research (Squire et al, 2013), there is no single, definitive approach to narrative analysis. Unlike many codified qualitative approaches which offer sequential, linear stages of analysis, the narrative methodological literature lacks any clear account of how to ‘do’ narrative analysis (Squire et al, 2013). This is most likely due to the diversity of narrative approaches: there are several ways to analyse and explore the narrative properties of data (Elliott, 2005). My analytic procedure is a series of co-occurring processes, which were conducted discretely for each individual participant (Figure 1).

Figure 1: Procedures for data analysis and interpretation in the current study



The model represents the non-linear analysis and the on-going indwelling and interpretation: even transcription and restorying are considered to be part of analysis (Emerson and Frosh, 2009; Reissman,

2008; Elliott, 2005). I produced 'clean transcripts' (Elliott, 2005; Appendix 8), in which I removed false starts, repetitions and non-lexical utterances, in order to focus on content and meaning.

I aim to transparently demonstrate reflexive awareness of my influence as researcher (Emerson and Frosh, 2009), without this forming the main focus of the analysis. I transcribed my main questions and comments, but omitted any 'attention markers' (Appendix 8). Furthermore, I fully acknowledge the co-construction of the narratives in this study, not only during their generation, but also during transcription, interpretation and analysis. I offer transparency at every stage, in order that readers can independently judge the trustworthiness/plausibility of my research claims (discussed further in Section 3.10 and Chapter 6).

I apply two different narrative analytic approaches to answer each research question, based on Polkinghorne's (1995) useful distinction between 'narrative analysis' and 'analysis of narratives'. Firstly, 'narrative analysis' refers to a rarely-practised way of analysing data, which is unique to narrative research. Data consists of a series of narrative elements (actions, events and happenings), which are analysed part-to-whole to create an emplotted, explanatory story. Polkinghorne (1995, p. 5) describes this as "the process by which happenings are drawn together and integrated into a temporally organized whole". Unlike traditional qualitative approaches to research, the aim is not to identify common themes between participants, nor seek to generalise to other cases; instead, the emphasis is on the particular and special characteristics of each individual story and the "complex interaction of elements that make each situation remarkable" (Polkinghorne, 1995, p. 11). This approach to exploring the uniqueness and complexity of individual stories, in order to produce knowledge of particular situations (Polkinghorne, 1995) is ideally suited to addressing RQ1, where I co-construct with participants an explanatory story about their CYP's later diagnosis of ASC.

Polkinghorne's (1995) second approach, 'analysis of narratives' describes a process of collecting complete stories as data and then using whole-to-part analysis to interpret taxonomies, categories and themes that run throughout the data. This deconstructive approach is familiar to most qualitative researchers, and analysis leads to an understanding of common elements (Polkinghorne, 1995). I apply this method to answer RQ2, by interpreting each participant's experiences of CYP receiving a later diagnosis of ASC, based on evaluative comments and linguistic devices interwoven throughout their narrative (explained further in Section 3.9.2). Unlike traditional qualitative analysis, the aim is not to identify themes from across participants: rather, to explore ideas throughout each individual story. The interview transcripts of Maria and Cathy were, therefore, analysed separately and discretely in relation to both research questions. Consistent with my claim of transparency, I now describe in detail the analytic procedures used to address each research question.

### *3.9.1 Research Question 1: How do parents' narratives illuminate an understanding of the reasons for later diagnoses of ASC?*

The process of emplotment can configure events into an overall story in four ways (Polkinghorne, 1995). Table 10 describes these four processes in the creation of participants' emplotted, explanatory stories across two phases: (i) the co-construction of the initial narrative segments during interview; and (ii) my subsequent analysis, interpretation and restorying. Findings for RQ1 are presented and discussed in Chapter Four.

*Table 10: Processes of emplotment in the current study*

<b>Processes of Emplotment</b>	<b>Phase 1: Co-construction of Narrative during the Interview</b>	<b>Phase 2: Researcher Analysis, Interpretation and Restorying</b>
Define the temporal range (the beginning and end)	This is defined by participants' use of 'chapters': both Cathy and Maria began during their pregnancy and ended with a chapter covering the present. Participants were invited to include optional future chapters.	I include participants' initial chapters (pregnancy) as some aspects were relevant to the overall plot. I omit their future scripts, as I judge them to be irrelevant to the mainline plot.

Provide criteria for the selection of relevant events	The plot (receiving a later diagnosis of ASC) was clarified with participants at the start of the interview. This served to support participants' selection of events and happenings that they deemed to be pertinent to the end point of the story (Polkinghorne, 1995).	Following the interview, I selected and interpreted events that either participants or I judge to contribute towards the 'mainline plot' (Gee, 1991). My criteria, supported by the narrative literature, are described in Appendix 7.
Order events in temporal sequence	The life chapters approach (based on McAdams', 1993, life history interview; Table 7) provided a temporal framework during the interview, but allowed participants to move freely between macro- and micro-narratives (Gergen, 1997), and between past recollections and current reflections.	Although the interview was roughly temporally sequenced by the chapters, people rarely tell complete stories sequentially (Gergen, 1997). The initial stages of my analysis, therefore, involves re-storying all narrative segments chronologically (Figure 1, Appendix 9).
Clarify the meaning and contribution of events in relation to the overall story	Participants used naturally occurring evaluative comments/linguistic devices throughout, and sometimes made overt links between the event/memory recalled and the overarching plot. On occasion, I asked follow-up questions to clarify the significance.	I used a matrix format (Appendix 9) to ensure that events and happenings did not become decontextualised from participants' reflections about the significance of events, as well as to provide a space for my own interpretations of the significance of events in relation to the overall story (detailed further in Appendix 7).

### *3.9.2 Research Question 2: How do parents evaluate the impact of the (later) timing of an ASC diagnosis?*

As well as being concerned with events, narrative research can produce rich experiential understandings (Patterson, 2013) by exploring the experience-centred aspects of participants' narratives (Squire et al, 2013). Analysis for RQ2 involves a process termed 'burrowing' (Connelly and Clandinin, 1990), in which events are explored in light of participants' emotions and cognitions about their experiences (Squire et al, 2013). I apply this descriptive approach (Polkinghorne, 1988), to explore parents' experience narratives concerning the impact of later diagnoses.

As illustrated in Figure 1, and described in Table 4 (Section 3.4.2), analysis for RQ2 involves identifying and interpreting the evaluative (Labov, 1972), descriptive (Polkinghorne, 1988) and experience-centred (Squire et al, 2013). I developed a matrix format (Appendix 11) to identify each participants'



experience-centred comments and linguistic devices interwoven throughout their story. Evaluation is not considered a distinct phase of a narrative, but instead “waves of evaluation penetrate the narrative” (Labov, 1972, p. 369). According to Labov (1972), evaluative clauses may be ‘external’, in which the narrator stops to overtly explain the point, or ‘internal’, in which the evaluative element is embedded and requires interpretation of lexical, syntactic, phonological and paralinguistic devices (Cortazzi, 1993). Detailed descriptions of my identification of internal and external evaluative devices are provided in Appendix 7. Based on the literature review (Chapter 2), my initial analysis was presented in matrix form (Appendix 11) to organise evaluative narrative extracts into pre-, during and post-diagnostic experiences, with the current study’s original focus on the impact of later diagnosis. This matrix format also provides a space for my on-going commentary and interpretation of participants’ evaluation of events and the experience as a whole (Appendix 11). Findings for RQ2 are presented and discussed in Chapter Five.

### **3.10 Trustworthiness and dependability: Rethinking validity and reliability**

Traditionally, science research has been judged against two main criteria: (i) ‘reliability’, defined as the stability and replicability of findings; and (ii) ‘validity’, defined as the creation of accurate and valid data which reflect an ‘external reality’ and can be generalised outside the research study (Elliott, 2005). This approach to evaluating research is inherently positivist and realist, suggesting that research should strive for objective, generalisable and fixed (reliable) understandings of social reality. These ideals are not appropriate to social constructionist research (Elliott, 2005) and may preclude some types of experiential and social knowledge (Aguinaldo, 2007).

As focusing upon the ‘paradigm wars’ is considered unproductive (Polkinghorne, 2007; Reissman, 2008), I argue instead for the importance of a universally agreed need to convince readers of the value of knowledge claims. This, I argue, can be achieved in different ways: “Different kinds of knowledge

claims require different kinds of evidence and argument to convince readers that the claim is valid” (Polkinghorne, 2007, p. 474). Many qualitative researchers agree that a strongly evidenced and persuasive argument for the validity of their knowledge claims is important (Polkinghorne, 2007), but the criteria for assessing the quality of research must be appropriate to the methodology (Smith, 2003): “The validity of a project should be assessed from within the situated perspective and traditions that frame it” (Reissman, 2008, p. 185).

Consequently, reliability can be helpfully redefined as the ‘dependability’ of the data (Webster and Mertova, 2007); and validity is often referred to the ‘trustworthiness’ of the data and of the analysis (Webster and Mertova, 2007) or the ‘credibility’ or ‘plausibility’ of the research (Polkinghorne, 1995). Yardley (2000) offers a useful framework of broad principles, against which I have considered the quality and trustworthiness of the current study (Table 11). These principles are particularly useful, as they are not prescriptive or rigid, but offer wide-ranging criteria, which can establish quality in diverse ways (Smith, 2003).

*Table 11: Steps taken to improve the quality of the current study, using Yardley’s (2000) principles*

Principle of Quality Research (Yardley, 2000)	Steps Taken in the Current Study
<b>Sensitivity to context</b>	
How sensitive is the research to the existing <i>substantive</i> literature?	<ul style="list-style-type: none"> <li>• Comprehensive and systematic literature review related to the substantive topic (Chapter 2)</li> <li>• Transparent search strategy (Section 2.2)</li> <li>• Clear rationale for conducting the current study as a result of gaps in the existing literature (Section 1.2)</li> <li>• Discussion (Chapters 4 and 5) clearly links the current study’s findings to the existing literature</li> </ul>
How sensitive is the research to the existing <i>theoretical</i> literature, in relation to the research method?	<ul style="list-style-type: none"> <li>• Clear rationale for the chosen methodology and awareness of the key concepts of the approach (Chapter 3)</li> <li>• Clear arguments for rejecting similar alternative approaches (Section 3.5)</li> <li>• Clear rationale for the chosen method (narrative interviews; Section 3.6)</li> </ul>
How sensitive is the research to the data itself?	<ul style="list-style-type: none"> <li>• The role of the researcher is acknowledged (Section 3.6.4), whilst privileging the meanings created by participants (Emerson and Frosh, 2009)</li> </ul>

		<ul style="list-style-type: none"> <li>• Transcription and data analysis procedures are highly transparent (Section 3.9; Appendix 7)</li> <li>• Participants' direct quotes are reported (Chapters 4 and 5)</li> </ul>
	How sensitive is the research to the participant-researcher relationship?	<ul style="list-style-type: none"> <li>• Good rapport was established (Appendix 3)</li> <li>• Careful consideration of ethical issues, including promoting beneficence (Section 3.7)</li> <li>• The influence of the researcher and the importance of reflexivity is discussed (Section 3.6.4)</li> </ul>
<b>Commitment</b>	To what extent does the researcher demonstrate knowledge of the substantive field and the chosen methods?	<ul style="list-style-type: none"> <li>• Extensive reading in relation to the existing substantive literature, leading to a comprehensive literature review (Chapter 2)</li> <li>• Extensive engagement with methodological texts in order to offer a detailed methodology chapter (Chapter 3)</li> </ul>
<b>Rigour</b>	How thorough has the researcher been in collecting and analysing data?	<ul style="list-style-type: none"> <li>• Transparent data collection procedures and data analysis techniques (Appendices 7-11)</li> <li>• Clear rationale for methodological decisions is offered throughout, made, as well as reasons for rejecting alternative approaches</li> <li>• Rigorous and in-depth data analysis procedures (Section 3.9 and Appendices 7-11)</li> </ul>
<b>Transparency</b>	How transparent is each stage of the research process?	<ul style="list-style-type: none"> <li>• Transparent and detailed descriptions of the following are offered in the write-up, including: <ul style="list-style-type: none"> <li>○ Selection and recruitment of participants (Section 3.8)</li> <li>○ Interview design, implementation and field-testing (Section 3.6; Table 7; Appendix 3)</li> <li>○ Data processing and analysis (Section 3.9; Appendix 7)</li> </ul> </li> </ul>
<b>Coherence</b>	How coherent are the arguments and knowledge claims made by the researcher? (Can claims be evaluated by the reader?)	<ul style="list-style-type: none"> <li>• A clear argument is made for the conclusions drawn in the study, supported by the evidence of the data collected (see discussion?)</li> <li>• As a result of the transparency of methods and data presentation, readers can also make their own judgements about the coherence of the research claims.</li> </ul>
	Does the research demonstrate coherence in the underlying philosophical assumptions?	<ul style="list-style-type: none"> <li>• My philosophical assumptions as a researcher are clearly outlined at the outset (Section 3.3)</li> <li>• All methodological decisions, including procedures for data analysis, were informed by my social constructionist stance. This stance is maintained and referred to regularly throughout the report.</li> </ul>

<b>Impact and importance</b>	Does the research contribute anything useful or important to the field?	<ul style="list-style-type: none"> <li>• A clear rationale for the study is provided (Chapter 1)</li> <li>• Findings of the current study are clearly related to the existing knowledge (Chapters 4 and 5)</li> <li>• Implications for research and practice are clearly presented and discussed (Chapters 4, 5 and 6)</li> <li>• The contribution and impact of the study is discussion (Section 6.2)</li> </ul>
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### 3.11 Summary

This chapter provides a clear rationale for the application of narrative methodology to answer the current study's research questions. I provide detailed description about the procedures for the generation, analysis and interpretation of narratives, as well as transparently reflecting on my influences throughout. The remaining chapters present and discuss the findings of the current study and discuss its contribution to theory, research and practice.

## CHAPTER FOUR: FINDINGS: RESEARCH QUESTION ONE

### 4.1 Overview

The presentation and discussion of findings from the current study are organised into three chapters: in Chapters 4 and 5, I discuss the findings and implications arising from RQ1 and RQ2 respectively and in Chapter Six, I discuss the current study's contribution to theory development, research and practice, including its limitations, and critically evaluate the trustworthiness and dependability of findings.

In the present chapter, I firstly outline my interpretation of the key findings from both participants, followed by a detailed presentation and discussion of findings for each participant in turn. In order to present the co-constructed explanatory story of the reasons for later diagnosis in each of Maria and Cathy's stories, I present findings in a series of temporally sequenced matrix forms (Maria: Tables 13-17; Cathy: Tables 18-22), outlining key events and their significance to the plot (receiving a later diagnosis of ASC). I use multiple direct quotes to privilege participants' voices and interpretations, as well as adding my own interpretations. Extracts from the in-depth analyses, from which these matrices are derived, can be found in Appendix 10. I include a summary and commentary for each participant in turn, and conclude the chapter with a discussion of findings from both participants in relation to existing literature (reviewed in Chapter 2) and the arising implications for research and practice.

## 4.2 RQ1 Key Findings: How do parents' narratives illuminate an understanding of the reasons for later diagnoses of ASC?

Maria and Cathy recounted two very different stories about their sons' (Kyle and Jake, respectively) receiving a later diagnosis of ASC. Findings indicate that the later AOD in both stories could not be explained by any single factor; rather, each case illustrated a set of highly individual and complex circumstances which contributed to the later diagnosis.

*Table 12: Summary of findings for RQ1: Possible explanatory or contributory factors leading to Kyle's and Jake's later diagnoses of ASC*

Participant 1: Maria (son = Kyle)	Participant 2: Cathy (son = Jake)
<ul style="list-style-type: none"> <li>Despite early parental concerns, Maria lacked awareness of ASC</li> <li>Professionals attributed Kyle's early behavioural presentation to Maria's parenting</li> <li>Maria did not receive an EP report (aged 4) which suggested the possibility of ASC</li> <li>Alternative diagnoses may have masked ASC (ADHD was suggested and dyspraxia was later diagnosed)</li> <li>Professionals did not consider Kyle's developmental history</li> <li>Professionals dismissed Maria's concerns (following brief observation)</li> <li>Wider family members (paternal grandmother) expressed scepticism about 'labelling' Kyle</li> <li>Maria developed awareness of ASC (and recognition of signs in Kyle) later through her role as a Teaching Assistant</li> </ul>	<ul style="list-style-type: none"> <li>There were no early parental concerns: Jake was considered 'comical' but not dysfunctional</li> <li>Initial concerns were not considered ASC-specific (motor skills difficulties noted at primary school; 'habits' such as blinking noted by parents)</li> <li>Cathy perceived that primary school staff <i>could</i> have identified ASC, but didn't</li> <li>Jake's diagnosis of 'Tourette's syndrome' may have masked signs of ASC</li> <li>The doctor who diagnosed Tourette's syndrome did not explore alternative hypotheses for Jake's 'habits'</li> <li>Concerns about Jake's behaviour at adolescence were initially normalised, then attributed to 'family issues'</li> <li>Jake's sudden academic progress and 'hidden difficulties' (subtle presentation of ASC) may have delayed/prevented parental and professional concerns</li> </ul>

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<ul style="list-style-type: none"> <li>• Kyle was well supported at primary school and perhaps did not <i>need</i> a diagnosis for his needs to be understood and met</li> <li>• Kyle's parents perceived a greater <i>need</i> for diagnosis at secondary school</li> <li>• The diagnostic process itself, including waiting times and poor information sharing, delayed the diagnosis (2 years)</li> <li>• Kyle was diagnosed at the age of 12 years</li> </ul>	<ul style="list-style-type: none"> <li>• Jake's parents perceived a later onset of problems requiring professional involvement (behaviour aged 13-15 years)</li> <li>• Cathy's consideration of a possible underlying condition occurred later</li> <li>• Cathy <i>perceived</i> a delay in waiting for Jake to give consent (3 weeks) and for the initial appointment (2 months)</li> <li>• Jake was diagnosed at the age of 16 years</li> </ul>
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#### 4.3 Maria and Kyle: Research Question One

Tables 13-17 outline my analysis and interpretation of Maria's explanatory story (comprised of her recollection of key events and our combined interpretations of them) about the reasons for Kyle's later diagnosis of ASC. From these, I conclude that several factors contributed to Kyle's later diagnosis. Firstly, Maria recounted that despite her early concerns about Kyle's development, she was not aware of ASC and did not draw connections to Kyle's presentation. Maria reflected that the later identification of Kyle's ASC may be related to her later awareness of ASC. Furthermore, professionals involved in Kyle's early years (including health visitors, social workers and the early years' special needs team) attributed his behaviour and sensory differences to Maria's parenting, thus delaying their consideration of ASC (or other conditions). Maria recounted a highly significant event: she never received an EP report suggesting the possibility of autism, which she believed led to the diagnosis being 'missed' at this stage. Maria reflected on how the exploration of alternative diagnoses (ADHD and dyspraxia) may have confused matters and, in my interpretation, may have masked the symptoms of ASC as a result of confirmation bias in attributing Kyle's difficulties to these other conditions. Professionals' approaches to exploring concerns may have also delayed the identification of ASC, as

their assessments omitted important information: Kyle's developmental history and his presentation across multiple contexts. Interestingly, the timing of Kyle's diagnosis may be partially explained by his being so well supported at primary school, with his parents' perceived *need* for a diagnosis emerging during the transition to secondary school. Finally, Maria interpreted delays in the diagnostic process itself, which took two years. She attributed this to a long waiting time and the paediatrician's poor information-sharing with the diagnostic panel.



*Table 13: Maria's event narrative: despite early parental concerns, ASC was never considered due to Maria's lack of awareness of the condition and professionals' attribution of Kyle's difficulties to her parenting*

Chapter	Age Range	Key Event/Memory
<b>Chapter 1:</b> "Pregnancy – didn't like to touch"	Pre-birth	Kyle was an unusual pregnancy, "he didn't move and he didn't like to be touched", which only came to light because Maria's "second pregnancy was totally different".
<b>Chapter 2:</b> "Health visitors – asked for help"	Birth - 3 years	Maria's first concerns related to Kyle's behaviour, describing him as an "ever-ready bunny" and "a Tasmanian devil".
		Maria noted early signs of ASC in hindsight, "sensory things, textures..." His pattern of language, physical development and his self-help skills were unusual: "his speech was late, [but] came all of a sudden... he doesn't do in-between stages".
<b>Chapter 3:</b> "Early Years - Possible autism"	3-5 years	In response to Maria's concerns, Kyle received rapid early professional involvement, "[I] explained my concerns [and] within a very short space of time, he got onto the early years' team".
<b>Chapter 5 –</b> "Social Services, S clinic, help"	5 years	Social services misinterpreted Kyle's sensory differences (involving his messy hands and removing his clothes) as a hygiene and social care issue.
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
With hindsight, Maria reflected on Kyle's early signs of being different and possible signs of ASC, "knowing what I know now, all his traits from a baby were so autistic but it just wasn't recognised whatsoever". Maria noted her developmental concerns about Kyle from an early age, but she did not "know about" ASC. Her emphasis on the rapid professional involvement at nursery served to highlight the severity of her concerns and her perception of Kyle's high level of needs at the time. She may have reinterpreted some of her early concerns as 'sensory issues', in light of the ASC diagnosis. During Kyle's early years, Maria asked for parenting support, but felt blamed for Kyle's difficulties: "I have someone that turns round and tells you it's your fault". This may have delayed the consideration (by parents and professionals) that Kyle may have had an underlying developmental/behavioural condition. Later, in Maria's Chapter 5, she began to question the attribution about her parenting, defending her experience, "I knew... what to expect for a child of that age" and "I am more consistent than a lot of parents". From this, she sought to assert that her parenting was not to blame for Kyle's behavioural presentation.		

Table 14: Maria's event narrative: Kyle's later diagnosis could be attributed to: (i) the missing EP report suggesting possible autism; (ii) exploration of alternative diagnoses; and (iii) professionals' approaches to exploring concerns

Chapter	Age Range	Key Event/Memory
Chapter 4: "Dr A, ADHD, Dyspraxia"	5 years (approx.)	Maria recounted a missing report: "I had a psychologist's report that I never received, which had the possibility that he was autistic. Or autism was mentioned, but I never got the report".
		Other diagnoses were explored: "[Doctor A] suggested that we thought it was ADHD... possibly... and dyspraxia... [ADHD was] just explored, so I never had a formal diagnosis that was signed off... He was diagnosed [with dyspraxia] at a later stage".
		Maria reflected the initial omission of Kyle's developmental history: "They never asked about his pregnancy, they never asked about his development", but this was the first thing the EP did. She indicated that one professional (unknown) dismissed her concerns and concluded "he is doing quite normally" after only observing him for 20 minutes.
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
Maria revisited the key event, 'the missing report', again at the end of the interview, highlighting her interpretation of its significance. She considered that ASC could have been identified: "if I had researched it at that point, he had all the symptoms", but she considered that it was "missed". Maria seemed to be making sense of alternative diagnoses, describing her understanding of symptom overlap, "it plays into the other stuff", and her lack of clarity, "diagnoses sort of things". She reported that she didn't "know about" autism, which I interpret to mean that she did not have any awareness of ASC in order to suggest exploring it at this stage. Maria indicated her views about how Kyle's developmental problems should have been investigated: implicitly, she suggested that professionals should have enquired about Kyle's developmental history. She also implied that her concerns should not have been dismissed on the basis of a single 20-minute observation of Kyle.		

Table 15: Maria's event narrative: speculative wider family influences on the timing of the diagnosis

Chapter	Age Range	Key Event/Memory
Chapter 6: "Working at school, finding a support system"	6 years- present	Maria noted that some members of the wider family (mainly her mother-in-law) did not accept that there were problems: "certain parties that wouldn't accept that there was a problem".
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
Maria reported some resistance from wider family members about "labelling" Kyle, which I speculate <i>could</i> have delayed the family's decision to seek a diagnosis, although Maria does not directly comment on whether this had an influence.		

Table 16: Maria's event narrative: Kyle's later diagnosis may be explained by his strong support at primary school and his parents' perceived increased need for a diagnosis at secondary school

Chapter	Age Range	Key Event/Memory
Chapter 7: "Transition primary – secondary"	9-11 years	Maria reported that Kyle was well supported at primary school. He had good relationships with staff and his 'needs' were understood and met, without the need for a diagnosis: "We hadn't needed any formal paperwork because where he went to school, they supported him extremely well".
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
It seems that being so well supported at primary school may have contributed to delaying the <i>need</i> for a diagnosis in Kyle's case. Kyle's parents "knew what the difficulties were" and understood his needs well, but decided to seek a formal diagnosis during the transition to secondary school, in order that others (including school staff and/or Kyle's peers) would recognise and support his needs.		

Table 17: Maria's event narrative: Kyle's later diagnosis may be explained by Maria's later knowledge about ASC and recognition of the signs in Kyle, as well as delays in the diagnostic process itself

Chapter	Age range	Key Event/Memory
Chapter 8: "Diagnosis, useless doctors"	10-12 years	Maria reflected on her later 'realisation' about the possibility of ASC, which occurred through working (as a teaching assistant) with a young person with Asperger's syndrome: "I knew later on... exactly what it was, because I'd met a little boy who at 12 was exactly like Kyle was at 5. The links between this young man and Kyle were the social cues."
		Maria reported that the diagnostic process took approximately two years, and that she waited 9 months prior.
		Maria stated, "I had to do all the paperwork... I got all the paperwork put up together by the Wednesday. By Thursday night, I was dropping it through the door. It went to panel on Friday and got diagnosed".
Chapter 9: "Breakdown level"	13 years	Due to Kyle's challenging behaviour, Maria described "getting proper help" from the EP. At this point, she described the EP as the one who "diagnosed him".
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
During Maria's Chapter 8, she reflected on her first parental recognition of autism-specific symptoms: "The links between this young man and Kyle were the social cues". She doesn't say, however, exactly when this realisation occurred, or indicate whether it was before or after the diagnostic process for Kyle had begun. Maria interpreted delays in the diagnostic process itself, due to her perception that she had the "same meeting" with the paediatrician three times: "I had gone through 7 months and nothing had been achieved", as well as his lack of information sharing: "he hadn't sent any information to anybody". A strong theme for Maria is that she had taken the lead. She contrasted the 9 months of waiting and 7 months of "achieving nothing", with her rapid collation of paperwork leading to the diagnosis being made by the panel: "within a week, I had got him diagnosed". In slight contradiction to her claim, "I had got him diagnosed", Maria later described the EP as the one who "diagnosed him", perhaps in reference to their joint compilation of the relevant paperwork and her perception of him as a 'significant person' when he offered support.		

#### 4.4. Cathy and Jake: Research Question One

Tables 18-22 outline my analysis and interpretation of Cathy's explanatory story (comprised of her recollection of key events and our combined interpretations of them) about the reasons for Jake's later diagnosis of ASC. In common with Maria's story, Cathy's story highlights the contribution and interaction of several complex influences on Jake's later diagnosis. Cathy reflected on the 'chance' aspect of her unique set of circumstances, not only in determining the timing of the diagnosis, but also in determining whether ASC would have been recognised at all. In contrast to Maria's story, Cathy recounted that she was not concerned about Jake during his early years, which could be attributed to Jake's mild/subtle presentation itself and the lack of resulting perceived impairment at that stage. Cathy's absence of concerns may also be explained by her limited experience of typical development, as a result of Jake being an only child and/or her self-declared lack of awareness of ASC.

Despite the primary school staff's concerns being non-ASC-specific (motor skills), Cathy questioned whether they could have recognised ASC: she considers that perhaps this was a missed opportunity for identification. Cathy's first concern related to Jake's 'habits' (such as blinking) which she initially attributed to eyesight problems, but was later diagnosed as 'Tourette's syndrome'. The doctor who made this diagnosis did not explore alternative explanations, which Cathy suggested, in hindsight, was another missed opportunity. She indicated that *she* did not think to suggest exploring ASC, as she did not know about it, and she reflected that the onus should be on professionals to explore alternative hypotheses comprehensively.

Cathy recalled a later onset of more severe problems requiring professional involvement: Jake's behaviour at adolescence. These concerns were initially normalised and dismissed by friends and family, then attributed by Cathy to "family issues". Furthermore, Jake's sudden academic progress at secondary school and his subtle presentation of ASC may have delayed/prevented both parental and professional concerns. Cathy recounted that her 'realisation' or consideration of a possible underlying condition occurred much later, whilst seeking help for family problems. Finally, Cathy reported a perception of delays in the diagnostic process: waiting for Jake to give consent (3 weeks) and for the initial appointment (2 months), although she acknowledged these as reasonable timescales, in hindsight, which did not strongly influence Jake's AOD.

Table 18: Cathy's event narrative: ASC was not considered in Jake's early years, due to Jake's subtle presentation, the absence of parental concerns and/or lack of parental awareness of ASC versus experience of typical development

Chapter	Age Range	Key Event/Memory
<b>Chapter 1:</b> "Special baby"	Pre-birth/ pregnancy	Cathy recounted: "I had been told several times that I couldn't have children... he was special from the start".
<b>Chapter 2:</b> "Early years"	Birth- 2.5 years	Cathy reflected on signs of ASC in hindsight, including Jake's unusual interests, preference for non-fiction and rote-learning: "there were signs then with the autism which I only can see now, looking back". She expressed no concerns at the time: "it wasn't anything that alarmed me".
<b>Chapter 3:</b> "New family unit"	2.5 – 4 years	Cathy reflected on Jake's unusual preference for real tools and materials: "My husband used to give him a drill, screws and a piece of wood".
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
Jake being "special from the start" was pertinent for Cathy: she expressed vindication that her parenting did not account for Jake's later behavioural difficulties (aged 13-15). During Jake's early years, his parents normalised his "comical ways" and were not concerned, but in hindsight Cathy made sense of Jake's unusual behaviours in light of the ASC diagnosis, for example, Jake's preference for real tools rather than toys and symbolic play. In my interpretation, Cathy's 'not noticing' could be due to Jake's subtle presentation, and/or Cathy's limited experience of typical development (Jake is an only child) and/or lack of awareness of ASC. As a toddler, Cathy portrayed Jake as 'different', but not 'disabled': no distress or dysfunction was apparent.		

Table 19: Cathy's event narrative: Jake's diagnosis of 'Tourette's syndrome' may have masked ASC symptoms; despite initial concerns not being considered ASC-specific, Cathy suggested that professionals may be accountable for not 'picking up' ASC at these stages

Chapter	Age Range	Key Event/Memory
<b>Chapter 4:</b> "Primary Years: Infants"	4-8 years	A diagnosis of 'Tourette's Syndrome' was made based on Jake's 'habits' (blinking, facial twitches and flicking his ears), but Cathy reflected on its validity: "There's a question mark now as to whether that was Tourette's or whether it was actually symptoms of autism". She highlights the ambiguity: "you don't really get a definite black and white answer".
<b>Chapter 5:</b> "Juniors"	8-11 years	Cathy recalled that further issues were "picked up" by staff at the junior school. Here, the support offered was primarily related to "mobility" concerns (gross and fine motor skills).
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
In hindsight, I interpret that Jake's 'habits' could be explained as sensory processing differences, such as visual/auditory filtering, or expressions of anxiety. Kyle's description of feeling compelled to blink and "his head feeling like it would explode" could be interpreted as a form of sensory and/or emotional overload. Although not autism-specific, Cathy recalled the way that motor concerns "have since become evidence of the condition". She shared her changed understanding of Jake's early differences: "that was all a symptom which we didn't know at the time". At the end of the interview, Cathy questioned: "was that the key time when 'it' could have been further investigated?" She defended her limited knowledge as a parent, "there was no relevance to me to bring it up" and placed the onus on professionals to have done this: "they know a lot more than me".		

Table 20: Cathy's event narrative: behavioural concerns at adolescence were normalised initially, then attributed to 'family issues'; Jake's hidden difficulties and sudden academic progress at secondary school may have delayed/prevented parental and professional concerns

Chapter	Age Range	Key Event/Memory
Chapter 6: "Development"	11-13 years	This chapter marked the discovery of Jake's strengths and academic potential. Jake channelled his 'special interest' (computers) positively to achieve something that was considered worthwhile by school staff and parents. Cathy described him becoming "obsessed" with his GCSEs.
Chapter 7: "A traumatic time"	13-15 years	Cathy recounted: "From 13 to 15, we started hitting a lot of problems, family issues". She considered the role of hormonal influences on his behaviour, "it was probably hormonal" and considered that the situation was 'hidden': "it doesn't come across how bad it was".
		Cathy described Jake's frequent lateness for school. She described a 'big argument' in the family, resulting in Jake moving in with his biological father. She recounted Jake's being unable to reflect upon what had happened, despite her request: "[I said] 'We have got to talk... you have got to understand what you've done'... and it just turned into more arguments".
Significance to Mainline Plot (How do these events help to explain the timing of the diagnosis?)		
Cathy seemed surprised by Jake's capabilities, "all of a sudden... he was achieving grades" and described her raised aspirations: "[he] wasn't what we thought he was going to be... [Previously] we thought he was going to just grow up and be a builder". She reflected further on signs of ASC in hindsight: his tendency towards solitude and project-work, "he was always happy just doing his own thing", and his better social relationships with teachers: "he doesn't get on with people his own age really". This was the first time that Cathy seemed to express any real concern. Interestingly, at this stage, she attributed difficulties to 'family issues', rather than to Jake himself. She described the 'hidden' nature of Jake's difficulties, "they don't really see the problems", and the lack of understanding from friends and family members, who normalised Jake's behaviour: "he is just a teenager... ours are the same". Jake's hidden difficulties were also unnoticed by the school, who admitted: "We overlook Jake because he is a good student". In hindsight, Cathy re-framed the arguments about Jake's lateness, in light of him not understanding social rules, "but he can't see that". With hindsight, Jake's inability to understand "what he had done", Cathy later saw as part of his ASC (poor social understanding), "looking back, it was part..." This phase marked the build-up of a family crisis point: "We [had] had enough of it" and perhaps the catalyst for seeking support and/or an explanation.		

Table 21: Cathy's event narrative: Jake may have been diagnosed later due to: (i) perceived later onset of problems and later parental support seeking; (ii) Cathy's later consideration of possible underlying conditions; (iii) perceived waiting times for Jake's consent and a referral; and (iv) professional dismissal

Chapter	Age Range	Key Event/Memory
Chapter 8: “The realisation and diagnosis”	15-16 years	Cathy was concerned about Jake’s “state of mind” and possible depression. She portrayed his unemotional and insensitive response to the family dog dying: “when you see that someone is upset, you think ‘they’re obviously not in the mood’... but Jake didn’t pick up on it”.
		Cathy requested help from the school liaison officer: “We are having all these problems at home”. Initially, the school liaison officer did not see the problems, but then “she did see a side to him which I don’t think she had realised”.
		Cathy suggested to the liaison officer that Jake may have an underlying condition which explained their family problems: “It was just a flippant comment. I said, ‘Do you think that there is some OCD?’”
		Cathy researched various diagnoses/conditions. Asperger’s syndrome seemed to be a ‘strong fit’: “I felt as though somebody must have written it about my son and about my life”.
		Cathy reflected upon how, at 16, she needed to gain Jake’s consent for all referrals. Cathy recalled waiting 3 weeks for Jake’s consent, then a further 2 months for the appointment: “We couldn’t go until the April, so we had to wait”.
		In the initial appointment, the social worker dismissed Asperger’s syndrome based on surface assumptions, “he can hold a conversation totally well with me” and her gathering “stupid details which aren’t anything to do with the problem”. The social worker suggested, “I think there may be a personality disorder”, but changed her mind, based on one “blunt” comment that Jake made and after reading Cathy’s own notes about his developmental history.
Significance to Mainline Plot (How do these events help to explain the timing of the diagnosis?)		
Initially, Cathy’s concerns were about ‘family issues’, prompting her to request family support, rather than seeking a diagnosis or support for Jake. Jake’s difficulties seemed to be hidden at school: the liaison officer said, “I didn’t realise because he is so well mannered at school”, which may have prevented school staff from raising concerns. Cathy began to express concern about Jake’s behaviour and comments, which she did not understand at the time, and she concluded, “I have reared a monster”. In hindsight, Cathy seemed to understand Jake’s differences in emotional processing and his difficulties reading social situations as part of his ASC, but at the time she expressed increasing concerns about his mental health. This marks the ‘realisation’ and key turning point for Cathy: “The penny just seemed to drop... we realised, ‘hold on a minute, could there be a condition rather than just a behavioural problem?’” Cathy’s internet research led to her realisation that ASC was a strong possible explanation. This may have actually <i>shortened</i> the time taken to identify and diagnose Jake with ASC. Cathy considered that seeking Jake’s consent delayed the process, “3 weeks went by and they [school staff] still hadn’t got the form filled in or signed by Jake”. She reflected upon how his consent may have prevented the entire referral and diagnosis: “If he had said, ‘no’... there wouldn’t have been a damned thing I could do about it”. As a result, she admitted to the hidden agenda of the referral: “Jake was under the impression that it was to do with family issues... but I knew it was because we thought he had got Asperger’s”. Cathy perceived that there was a delay in the referral process itself, due to a two month waiting time for the initial appointment. In the appointment, Cathy reflected on how ASC was initially dismissed by the social worker. This further emphasises the sometimes ‘hidden difficulties’ of ASC and the risk of diagnoses either being missed or inaccurately suggested,		



due to 'snap judgements' based on brief and superficial information and/or limitations in professional knowledge and skills. Cathy's own notes about Jake's developmental history (which she chose to write unprompted by professionals) served to change the social worker's mind.

Table 22: Cathy's event narrative: Cathy's reflections of the most significant opportunities for ASC to have been identified in hindsight

Chapter	Age Range	Key Event/Memory
<b>Chapter 9:</b> "Moving forward"	17 years plus	Cathy reflected on the timing of the diagnosis. She revisited two time-points when she thought ASC could and should have been identified. Firstly: "I think it <i>could</i> have been picked up at primary school, but I can understand why it wasn't"; and secondly: "It <i>should</i> have been picked up at the hospital... I think they <i>should</i> have investigated other things as well".
<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)		
Reflecting on the whole story, Cathy attributed the realisation and identification of ASC to chance ('a fluke') and repeated "it would have been so easy" [to have missed it completely]. Cathy's final poignant comment "we may never have known" indicated her perception that Jake's diagnosis only occurred because of a complex set of 'chance' circumstances, within which if anything had been different at any stage, ASC may have been 'missed' completely.		

#### 4.4 Discussion of findings for Research Question One

Both stories in the current study suggest that the reasons for later diagnoses of ASC are not simple: each story has a unique and complex set of circumstances, which participants and I interpret to explain the later diagnoses. To situate my findings within the context of existing research, I now discuss my findings in relation to the literature reviewed in Chapter Two, organised by three broad areas: (i) demographic factors; (ii) the interaction between child presentation and parental concerns; and (iii) professional factors and service variation.

##### 4.4.1 Demographic factors

Despite a wealth of research exploring the possible influences of demographic factors on AOD, findings from the literature review (Chapter 2) revealed largely contradictory and inconclusive research evidence (with ethnicity as the exception). The current study proposes a possible explanation. Isolated demographic variables<sup>7</sup> were not directly alluded to by either Maria or Cathy as contributing to the AOD. Rather, findings suggest that demographic variables may interact in different ways with the unique set of surrounding circumstances and contribute to the later AOD.

For example, I interpret that family factors, such as birth order and sibling status, may have *indirectly* influenced the AOD in Maria and Cathy's stories. In Maria's case, although Kyle was her first-born child (a risk factor for later diagnosis: Fountain, 2011; Rosenberg et al, 2011), she described her experience of typical child development from her own younger sibling and from baby-sitting. Whilst her comparison of Kyle's atypical presentation did lead to earlier and more severe concerns, this was not sufficient to secure an earlier diagnosis, due to other complicating factors (discussed in Section 4.4.2

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<sup>7</sup> Demographic variables reviewed in Chapter Two included: gender, ethnicity, socio-economic status, birth order, sibling status, parental education.

and 4.4.3). In Cathy's case, her absence of early concerns could be explained by her lack of awareness of typical development (Jake is an only child), although I acknowledge the possibility that Cathy had experience that she did not disclose. This could also be explained by Jake's subtle presentation itself (discussed in Section 4.4.2). Both Maria and Cathy acknowledged their lack of awareness of ASC may have contributed to later AOD: possibly due to neither having relatives with ASC, a factor often associated with earlier parental recognition (Adelman, 2010; Mishaal et al, 2014; Herlihy et al, 2015; Twyman et al, 2009).

Furthermore, existing literature has explored the role of parental education. Although there are mixed findings (Daniels and Mandell, 2013; Mishaal et al, 2014), some research indicates higher parental education is associated with earlier diagnosis (Fountain, 2011; Rosenberg et al, 2011; Daniels and Mandell, 2013). Both Maria's and Cathy's level of parental education (admittedly based on my observations of their articulate oral communication and competent written skills) may have contributed to a relatively *earlier* diagnosis. In Maria's case, she pro-actively co-ordinated the collation of paperwork for the diagnostic panel, and in Cathy's case, upon finding Asperger's syndrome on the internet, she documented salient aspects of Kyle's developmental history, which influenced the social worker to reconsider possible ASC. These events may have led to slightly *earlier* diagnosis in each case or indeed reduced the likelihood of ASC not being recognised at all.

#### *4.4.2 Child presentation factors and parental concerns*

Child presentation factors and parental concerns may have contributed to the later diagnosis of ASC in both of the current study's stories. Both Kyle and Jake attended mainstream secondary schools and their inferred relatively higher communicative and adaptive functioning is an established risk factor for later diagnosis (Fountain et al, 2011; Mishaal et al, 2014). However, their early behavioural presentations were dissimilar, and in each case strongly linked to differences in the age, severity and

type of parental concerns. Despite these dissimilarities, Maria and Cathy *both* experienced a relatively late diagnosis, further emphasising the complexity of later diagnoses.

Cathy expressed no early parental concerns and Jake had no early professional involvement. This could perhaps be explained by his milder presentation, which is known to be associated with later AOD (Rosenberg et al, 2011). Jake's eventual diagnosis was 'Asperger's syndrome', which tends to be diagnosed 'later' (on average 7.2 years; Mandell et al, 2005). This is consistent with Zwaigenbaum's (2012) argument that early detection of ASC is complicated by its heterogeneous presentation and some suggest that the earliest *possible* age of detection of ASC is limited by its behavioural definitions and diagnostic criteria (Pierce et al, 2009). Furthermore, others suggest a lifespan perspective in which certain features of ASC may not manifest until later (Frith, 2003; Karim et al, 2012). This raises further important conceptual questions about when it is *possible* to identify ASC: were Jake's early indicators (identified in hindsight) 'missed' by Cathy and school professionals, or were they not sufficient to be classified as 'requiring support' (based on DSM-5 criteria; APA, 2013, Table 1) until Jake's emotional and behavioural regulation became significantly negatively affected as a result of increased demands during adolescence?

Conversely, Maria was highly concerned about Kyle from an early age, marked by her request for support and emphasis on Kyle's early professional involvement. The literature suggests that greater severity of parental concern has been associated with 'earlier' diagnosis (Perryman, 2009; Daniels and Mandell, 2013). Maria's earlier and more severe concerns about Kyle could partially explain his slightly earlier diagnosis than Jake (12 years versus 16 years). Nonetheless, Kyle's diagnosis was still relatively 'late' (12 years). Maria's story seems to resonate with Guinchat et al's (2012) finding that parents who express *general* concerns (rather than ASC-specific) tend to receive a later diagnosis, even when they have expressed earlier concerns. The type of first concerns may have contributed to later AOD in both cases.

Earlier diagnosis has been associated with the child ‘having’ ASC-specific symptoms, such as language, social skills, atypical behaviour and unusual mannerisms (Twyman et al, 2009; Barrie, 2010; Daniels and Mandell, 2013; Jónsdóttir et al, 2011; Mandell et al, 2005; Valicenti-McDermott et al, 2012; Maenner et al, 2013). Existing research adopts a realist position, suggesting that the child essentially *has* these symptoms, but from the findings of the current study, I consider that the *interpretation and attribution* of behaviours by parents and professionals is more relevant to the AOD. Both Maria and Cathy’s initial concerns were initially attributed to non-ASC behavioural problems, which has previously been associated with later diagnosis (Adelman, 2010; Perryman, 2009; Daniels and Mandell, 2013). In Maria’s story, professionals attributed Kyle’s early behavioural difficulties to her parenting. In Cathy’s story, primary school staff were first concerned about Jake’s motor skills, whilst she became concerned about his ‘habits’ and possible ‘eyesight problems’. The current study demonstrates that defining ‘ASC-specific concerns’ is difficult, and depends largely on whether ASC has been suggested or considered. In both cases, these first concerns *could* have been interpreted differently, through the ‘lens’ of ASC, which is demonstrated by both parents in their reflections on early indicators with hindsight. This is supported by Molina’s (2014) finding that some parents may notice early unusual behaviour without being concerned enough to seek help (i.e. Cathy’s story), or drawing connections to ASC (i.e. both stories). This has implications for more comprehensive exploration of initial parental concerns.

I consider that the alternative diagnoses made in both stories are highly relevant to the later AOD. In Maria’s story, ADHD and dyspraxia were suggested when Kyle was approximately 4, with ADHD being explored but not diagnosed, and dyspraxia being later diagnosed. In Cathy’s case, Jake was diagnosed with Tourette’s syndrome aged 6-8 years. Existing research consistently suggests that receiving a prior diagnosis of another behavioural/developmental condition is associated with later ASC diagnosis (Adelman, 2010; Daniels and Mandell, 2013; Jónsdóttir et al, 2011). In particular, ADHD (Frenette et

al, 2011), hearing impairment, oversensitivity to pain and psychiatric or neurological conditions (Daniels and Mandell, 2013; Mandell et al, 2005) have been associated with later AOD. The existing literature speculates about the possibility that alternative diagnoses may ‘mask’ the symptoms of ASC. It seems plausible that upon diagnosis of any behavioural/developmental condition, confirmation bias leads to all subsequent concerns being attributed to that particular condition, thus reducing the perceived need to explore alternative (or additional) explanations. By holistically keeping individual stories intact, the current study offers a new perspective on this (discussed in Section 4.4.3).

#### *4.4.3 Professional factors and service variation*

Later AOD in both stories in the current study may be partially explained by service procedures and professional factors in the recognition, assessment and diagnosis not only of ASC, but also of other related behavioural/developmental conditions. This could explain the influence of alternative/additional diagnoses in predicting later diagnosis of ASC (Section 4.4.2).

Neither Maria nor Cathy suspected autism during early childhood, due to their self-disclosed lack of awareness of ASC. They both placed the onus on professionals to have recognised and identified ASC. The logical conclusion is that professionals simply ‘missed’ ASC, with the simple implication that more professional training and awareness-raising is needed. However, in both cases the influence of other suspected and/or diagnosed conditions (ADHD and dyspraxia in Kyle’s case; Tourette’s syndrome in Jake’s case) highlights that raising further awareness of ASC, in isolation, would not be sufficient.

During the exploration/diagnosis of these other conditions in both stories, the possibility of ASC was not overtly considered or eliminated (it if had been, such as in Maria’s missing EP report, it certainly wasn’t communicated to Maria or Cathy). Whilst NICE guidelines for the recognition, referral and diagnosis of ASC (NICE, 2011) emphasise the importance of eliminating differential diagnoses

(including ADHD and dyspraxia), guidance for other conditions (those identified in the current study) do not mirror this. NICE guidelines for diagnosing ADHD (NICE, 2008) state that full developmental histories should be taken, but gives no rationale for this (i.e. excluding other developmental conditions). Furthermore, this guidance specifies that “care in differential diagnoses is needed” (NICE, 2008, p. 4), but those listed (“disorders of mood, conduct, learning, motor control and communication, and anxiety disorders”) are framed as common co-existing conditions rather than alternative explanations. Currently, there are no NICE guidelines for dyspraxia or for Tourette’s syndrome. The NHS (National Health Service, 2014) website for dyspraxia (sometimes known as Developmental Coordination Disorder) only suggests eliminating medical conditions (such as cerebral palsy and muscular dystrophy). The NHS (National Health Service, 2015) website for Tourette’s syndrome explains that “tic-like behaviours” can be caused by ASC (such as mannerisms or stereotypies), and states that it is necessary to rule this out, although it seems that in Cathy’s story, this did not occur. Based on the findings of the current study, in conjunction with these guidance documents, it seems likely that when ASC is suspected, a comprehensive assessment would take place (assuming that NICE guidelines are followed). Conversely, if other conditions (such as ADHD, dyspraxia and Tourette’s syndrome) are initially suspected, they could be diagnosed without fully eliminating the possibility of other explanations and/or conditions, such as ASC.

Both Maria and Cathy alluded to the lack of comprehensive assessment at various stages. Maria expressed surprise that professionals did not enquire about Kyle’s developmental history, whilst Cathy expressed frustration with the social worker who focused on “stupid details which aren’t anything to do with the problem”. Both parents also recalled episodes of feeling dismissed. Maria indicated that one professional (unknown role) dismissed her concerns and Cathy recounted the social worker quickly dismissing the possibility of Asperger’s during the initial appointment. The existing literature highlights the importance of professionals listening to parents’ concerns and taking them seriously (Mansell and Morris, 2004; Barrie, 2010; Howlin and Moore, 1997; Rose, 2011; Fleischmann, 2004; Glazzard and

Overall, 2012; Mann, 2013). Listening to and taking parents' concerns seriously is also recognised in NICE (2011) guidance for ASC, but in order for professionals to refer to this document, ASC must have been suspected in the first place, which was not the case in either story. This emphasises the importance of noting parents' concerns, regardless of the type of initial concerns, in order to build a comprehensive picture of the presenting issues and fully explore possible explanations. This complements Adelman's (2010) finding that comprehensive assessment in response to parental concerns is associated with earlier diagnosis of ASC.

Furthermore, NICE (2011) guidance advocates gathering information about the child in multiple contexts. In the current study, such comprehensive assessment was not evident. Maria described one professional (unknown role) who concluded that ASC was not suspected after observing Kyle in a clinic situation for 20 minutes, whilst Maria described how Tourette's syndrome was diagnosed based on her own accounts of Jake's 'habits', without the doctor observing it first-hand or triangulating information from other sources, such as school professionals. Whilst the importance of information from multiple contexts is noted in guidance for diagnosing developmental/behavioural conditions, including ASC (NICE, 2011) and ADHD (NICE, 2008), it seems that this is not always practised. In Maria's case, Kyle's early behavioural problems were attributed to her parenting skills, without other explanations being sufficiently explored or eliminated.

The length of the diagnostic process<sup>8</sup> may partially explain later diagnosis of ASC, supported by existing evidence that the duration of the diagnostic process is on average between 2-4 years (Rose, 2011; Siklos and Kerns, 2007; Howlin and Moore, 1997). In the current study, delays in the diagnostic process were perceived by both Maria and Cathy. In Maria's case, the two-year diagnostic period was considered unnecessarily long, hindered by a long unexplained waiting time and poor information

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<sup>8</sup> The length of the diagnostic process is loosely defined as the period from first suspected ASC (or referral for assessment) to the diagnosis being confirmed.



sharing. Cathy perceived that the diagnosis was hindered by seeking Jake's consent (3 weeks) and in waiting for the initial appointment (2 months). She acknowledged that these were probably reasonable waiting times, which did not significantly contribute to the Jake's later diagnosis, but the noteworthy emotional impact of the perceived waiting time is discussed in Chapter Five.

## **4.5 Implications (RQ1)**

### *4.5.1 Implications for Practice*

The current study's exploration of the reasons for later AOD raises important implications for practice, not only for EPs, but also for other medical and educational professionals. There is a lot to be learned from existing ASC guidance documents (e.g. NICE, 2011), in order to improve the accuracy (or 'helpfulness') and timeliness of appropriate 'formulations' (discussed below) about the needs of CYP including: (i) exploring differential diagnoses and alternative hypotheses; (ii) drawing on information about the child in multiple contexts; (iii) multi-agency clinical judgement; (iv) considering the child's full developmental history; and (v) taking parental concerns seriously. I suggest these guidelines should be followed not only when ASC is suspected (NICE, 2011), but also when *other* developmental/behavioural concerns are raised.

It seems that confusion around differential diagnoses, which was associated with later AOD in the current study and in existing research, could be addressed by all professionals adopting a more comprehensive hypothesis-testing approach, in which various suggested explanations ('hypotheses') for presenting issues and behaviour are explored. Currently, educational psychologists are trained to use such frameworks (Beaver, 2011; Kelly et al, 2008) in order to explore multiple possible hypotheses to reach the best possible explanation for a CYP's presenting issues: a 'formulation' (BPS, 2011;

Johnstone and Dallos, 2014). This involves gathering information about the CYP and the situation from multiple contexts and from other professionals where necessary. The formulation may include diagnosis of a behavioural/developmental condition, or may arise from the child's life experiences<sup>9</sup>.

I propose that a more 'joined-up' approach is needed to assess and formulate the needs of CYP with presenting behavioural/developmental issues, not only when ASC is suspected, as already recognised in NICE (2011) and practised in the Local Authority (Chapter 1), but also when other concerns are raised or other conditions are suspected. I consider that there is potential for a combined multi-agency pathway for the assessment and formulation of behavioural/developmental concerns (including possible diagnosis of conditions). This could take a similar form to the existing multi-agency panel for assessment and diagnosis of ASC in the current study's Local Authority (Section 1.1.2), but expand the remit to explore a wider range of possible explanations. As a multi-agency panel, there would be scope to draw upon specialist knowledge of particular conditions from different professional agencies, in order to reach multi-agency agreement about the best possible explanation (formulation) for the child's presenting issues. I acknowledge that in recent times of austerity, such comprehensive assessment and 'gold standard' multi-agency working may be difficult to establish (Karim et al, 2012). This should not hinder the aspiration; rather, it should drive research to explore the possibilities, through further research (discussed in Section 4.5.2).

Furthermore, in light of the absence of parental recognition of ASC in both stories, I do not suggest that raising more general public awareness of ASC is necessarily an appropriate solution; rather, that professionals should be more transparent in the hypotheses that they are exploring and provide information to parents about possible/suspected conditions, to prompt parents to share appropriate information. This would strengthen parental participation, which is promoted by recent legislation (Lamb, 2009; DFE/DOH, 2015; Children and Families Act, 2014). Related to this was the EP report that

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<sup>9</sup> For example: insecure or disrupted attachment, neglect or trauma.

Maria never received, which had raised the possibility that Kyle had autism. This raises two important implications: one quite simply highlights the importance of the administrative task of checking that reports have been sent and received, and the other, suggests that if professionals do suspect autism, this should be discussed with parents face-to-face and decisions should be made about whether to refer to diagnostic teams (in line with the NICE pathway, 2011).

Lower parental education should not form a barrier to receiving a timely diagnosis. Whilst Maria coordinated paperwork for Kyle's diagnosis and Cathy wrote Jake's developmental history based on her own research about ASC, other parents may not have these skills. This strengthens my argument that the onus is on professionals to provide appropriate information and to support parents to provide relevant and comprehensive information about their CYP's developmental history. This should be practised with caution: providing checklists to parents could engender confirmation bias and false positive identification of conditions, and should be practised with sensitivity, as NICE (2011) guidelines suggest that parents may experience distress if they have not previously suspected a developmental/behavioural condition.

#### *4.5.2 Implications for Research*

The interesting research implications arising from RQ1 are that the current study's narrative methodology afforded a new perspective, as a result of its focus on exploring complete individual stories across time (parents' explanatory narratives of receiving a later diagnosis of ASC). There is scope for future research to employ a similar methodological approach, further to explore the complex reasons for later diagnoses of ASC. Arising from the current study, it would be interesting to explore parent narratives of differential diagnoses, with narrower participant recruitment criteria to target those with such experiences. It would also be interesting to explore the narratives of the various professionals, who make these clinical judgements, such as in Karim et al's study (2012).

Furthermore, arising from the practice implications about the possible value of hypothesis-testing and formulation in assessing and diagnosing behavioural/developmental conditions, further research could pilot a multi-agency model for a single assessment pathway, in which a wider variety of developmental concerns (for example, including consideration of possible ASC, dyspraxia, ADHD and other conditions and concerns) would be considered by a multi-agency panel using a model of hypothesis-testing and formulation, as opposed to the current diagnostic model of exploring only one hypothesis at a time (for example, asking “could ASC explain these needs?”). This should involve extensive prior research, beginning with a comprehensive critical literature review, to establish which conditions should be included and excluded, and which professional agencies should be involved.

## CHAPTER FIVE: FINDINGS: RESEARCH QUESTION TWO

### 5.1 Chapter overview

I begin this chapter with a brief discussion of the unanticipated richness of the data generated by the current study and my editorial decisions to manage this. I summarise the key findings from RQ2, followed by detailed presentation and discussion of findings from each participant in turn. In order to privilege participants' meanings and descriptions about the impact of the AOD, I present several direct quotes (italicised) from their experience-centred narratives in matrix form (Maria: Tables 24-26; Cathy: Tables 27-19), alongside my own interpretations of their experiences. Underlined extracts denote the key linguistic and evaluative devices analysed in relation to the criteria (Appendix 7). The initial analysis matrix can be found in Appendix 11 (discussed in Section 5.2). I summarise and comment on the impact of the later diagnosis for Maria and Cathy. Finally, I discuss these findings in light of existing research literature (reviewed in Chapter 2) and consider the implications for research and practice.

### 5.2 Unanticipated depth of data

I now reflect upon the unforeseen prolific nature of the data generated by the interviews with Maria and Cathy in relation to their experiences, and the unanticipated depth and richness of the analyses this afforded. I attribute this to the flexible and evolving design of the current study, which Robson (2011) suggests should be addressed with adaptability and flexibility from the researcher. For reference, my detailed initial analysis of participants' experiences is included as Appendix 11. Ultimately, I intend to publish this research thesis as two distinct, but cross-referenced, studies in relation to each research question. This should afford expanded opportunity to discuss participants' experience-narratives in detail, relating to their pre-, during and post- diagnostic experiences (as guided by the literature reviewed in Chapter 2), as many aspects of their experience were not included.

In particular, I excluded Maria's frequent digressions from the mainline plot to discuss the everyday experiences of living with ASC (Section 2.4.1); this is not the focus of the current study and is further explained in Appendix 7. Within the remit of the current doctoral thesis, I make the editorial decision to select only aspects of parents' experience that specifically relate to RQ2: the impact of the later AOD.

### **5.3 Key findings: How do parents evaluate the impact of the (later) timing of an ASC diagnosis?**

Although Maria and Cathy's narratives share the common plot of receiving a later diagnosis of ASC for their sons, their experience narratives and my interpretation of them were largely dissimilar, particularly their experiences pre-diagnosis. Key findings from RQ2 are summarised in Table 23.

Table 23: RQ2 summary of key findings

Timescales	Maria's Experience Narrative	Cathy's Experience Narrative
<b>Pre-diagnosis</b> (including all memories/events from pregnancy to the 'realisation' and referral)	<ul style="list-style-type: none"> <li>• Maria expressed early and severe concerns</li> <li>• She felt blamed and judged</li> <li>• She experienced a lack of explanation and uncertainty</li> <li>• Despite professional involvement, Maria felt unsupported</li> <li>• With hindsight, Maria felt angry and disappointed that she never received an early EP report suggesting possible ASC</li> <li>• Maria considered that an earlier diagnosis may have led to improved understanding and/or additional support</li> <li>• The 'need' for diagnosis was considered highly important during Kyle's primary-secondary school transition</li> </ul>	<ul style="list-style-type: none"> <li>• In Jake's early years, Cathy was not concerned at the time</li> <li>• The Tourette's syndrome diagnosis (aged 6-8 years) seemed to invoke more curiosity than concern</li> <li>• At adolescence, Jake's behaviour led to Cathy's 'nadir' moment: "a traumatic time"</li> <li>• Cathy experienced uncertainty, frustration and a lack of understanding from others about Jake's 'hidden' difficulties</li> <li>• She indicated that an earlier diagnosis could have led to improved understanding, help and advice: leading to better preparation for adolescence and reducing distress</li> </ul>
<b>Diagnostic period</b> (defined as the time between the 'realisation'/referral and the confirmed diagnosis)	<ul style="list-style-type: none"> <li>• Maria perceived that the process took too long (2 years)</li> <li>• Maria felt angry, frustrated and "badly let down" by the paediatrician's poor information-sharing</li> <li>• As a result, Maria pro-actively decided to co-ordinate professionals' information-sharing</li> <li>• Upon receiving the diagnosis, Maria expressed "gratification"</li> <li>• The diagnosis was considered to improve parents' understanding and help to explain Kyle's needs to others</li> </ul>	<ul style="list-style-type: none"> <li>• Cathy expressed gratitude that her concerns were understood by secondary school staff (Jake was 15-16 years)</li> <li>• She expressed anxiety and hopelessness that at "one month off 16", it might have been too late to get help</li> <li>• Seeking Jake's consent was a possible barrier to diagnosis and support, leading to fear, desperation and powerlessness</li> <li>• Cathy was "gutted" about the waiting time (2 months)</li> <li>• She expressed frustration, disappointment and disbelief that the appointment was "wasted", creating further uncertainty</li> <li>• The process itself was considered "very straightforward"</li> </ul>
<b>Post-diagnosis</b> (participants' contemporaneous recollection of their experiences post-diagnosis and their	<ul style="list-style-type: none"> <li>• Unrelated to the diagnosis itself, Kyle's behaviour post-diagnosis prompted Maria's worst time overall</li> <li>• Prior to diagnosis, 'not knowing' was a source of stress, but, post-diagnosis, this did not appear to reduce</li> <li>• Maria described being at "breakdown level" indicating her vulnerability and sense of feeling out of control</li> </ul>	<ul style="list-style-type: none"> <li>• The situation was considered improved for Jake's parents, including reduced worry and increased understanding</li> <li>• Cathy noted a positive impact for Jake on his self-awareness and understanding: the later timing may have been beneficial for Jake</li> <li>• Cathy noted feelings of regret and possibly guilt</li> </ul>

reflections in hindsight)	<ul style="list-style-type: none"> <li>• Overall, she reflected on her perception of 'having to fight' and the impact on her own identity: "you become horrible!"</li> <li>• Maria suggested that Kyle has figuratively "hit every pothole", describing the experience as "an endurance process"</li> </ul>	<ul style="list-style-type: none"> <li>• She reflected on the 'chance' element: "it would've been so easy [to miss the ASC completely]"</li> <li>• Cathy considered that an earlier diagnosis may have been "a lot less traumatic", but at no point suggested a need, desire or possibility for ASC to have been identified any earlier than 6-8 years</li> </ul>
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### *5.3.1 Maria and Kyle: Research Question Two*

Maria's narrative of her experiences is presented and discussed in Tables 24-26. From this, I conclude that pre-diagnosis, Maria expressed early and severe concerns about Kyle's behaviour. She felt blamed and judged: his behaviour was attributed to her parenting skills and his sensory differences were interpreted as a social care issue. As a result, Maria felt unsupported. With hindsight, Maria felt angry and disappointed that she never received an EP report suggesting autism when Kyle was 4 (which she discovered when he was assessed at 12). Upon reflection, Maria considered that an earlier diagnosis may have afforded improved understanding and/or additional support, but she indicated that the perceived 'need' for diagnosis was highest during Kyle's transition from primary to secondary school, so others could understand his needs.

The diagnostic period took two years in Maria's story, which she perceived to be too long, and reported feeling angry, frustrated and "let down" by the paediatrician's lack of information-sharing. Consequently, Maria decided to be pro-active in co-ordinating professionals' information-sharing. Upon confirmation of the diagnosis, she expressed gratitude. Post-diagnosis, Maria considered her understanding of Kyle's needs was improved and that this aided the explanation of Kyle's needs to others (primarily secondary school staff). Unconnected to the diagnosis, Maria described Kyle's behaviour post-diagnosis as the 'nadir' experience and crisis point. Despite 'not knowing' being a source of stress prior to diagnosis, Maria showed no indication post-diagnosis of this reducing, suggesting that, for her, the diagnosis was not an end in itself: further support was sought and provided by the EP. Overall, Maria reflected on her perception of 'having to fight' and the impact on her own identity: "[I'm a] stubborn bulldog". She considered that Kyle had figuratively "hit every pothole" and described the experience of securing an accurate diagnosis as an "endurance process".

Table 24: Maria's experience narrative: Pre-diagnosis

Timescales	Maria's Experience Narrative
<b>Chapter 2:</b> Health visitors – asked for help (birth to 3 years)	<ul style="list-style-type: none"> <li>• <u>Imagine</u> having an 'ever-ready bunny' running around the place.... He was like a Tasmanian devil... Extremely energetic.</li> </ul>
	<ul style="list-style-type: none"> <li>• They <u>weren't much help at all...</u> People <u>just didn't pay any attention</u> to what I was telling them.</li> </ul>
	<ul style="list-style-type: none"> <li>• I have someone that turns round and tells you <u>it's your fault</u> that your child's just the way they are.</li> </ul>
	<ul style="list-style-type: none"> <li>• I had to have <u>a very big decision about whether to have another child...</u> <u>At that time we didn't know what it was.</u> The thought of having two of them like him running around would be a nightmare.</li> </ul>
<b>Chapter 3:</b> Early Years (3-5 years) 'Possible autism'	<ul style="list-style-type: none"> <li>• <u>Within a very short space of time,</u> then he got onto the early years team.</li> </ul>
	<ul style="list-style-type: none"> <li>• He started school in the <u>January and by the time we got to Easter,</u> we had the Early Years team involved with him.</li> </ul>
<b>Chapter 4:</b> Dr A, ADHD, Dyspraxia (age 5-ish)	<ul style="list-style-type: none"> <li>• This is where I got <u>let down...</u> because I had a psychologist's report that I never received, which had the possibility that he was autistic... <u>but I never got the report.</u></li> </ul>
	<ul style="list-style-type: none"> <li>• That made me <u>really angry...</u> I was <u>f-</u> I was <u>more upset</u> and <u>disappointed</u> at that point.</li> </ul>
	<ul style="list-style-type: none"> <li>• If I had known... a lot of that <u>would have made sense</u> and then <u>that bit wouldn't have happened</u> and then <u>this bit would have been a lot easier</u> <u>because the support would have been a lot easier</u> because I would have had him statemented.</li> </ul>
<b>Chapter 5 –</b> Social Services, 'S' clinic, help (age 5)	<ul style="list-style-type: none"> <li>• They were concerned about his hygiene 'cause he had a habit of hands..., <u>as little boys do,</u> smelly sort of things. We'd dealt with an awful lot of <u>issues with Kyle – sensory and whatsoever....</u> I was <u>extremely annoyed</u> at them.</li> </ul>
	<ul style="list-style-type: none"> <li>• <u>Not being believed...</u> rather than going, "oh no, <u>that's not a problem,</u> he is doing quite normally" [after] being with the child for <u>just 20 minutes...</u></li> </ul>
	<ul style="list-style-type: none"> <li>• It is <u>like being judged</u> that it is <u>your fault...</u> You feel "<u>why has no-one ever taken me seriously?</u>"</li> </ul>
	<ul style="list-style-type: none"> <li>• When I <u>had my breakdown</u> on that one day, I contacted the child and disabilities team.</li> </ul>
<b>Chapter 6:</b> Finding a support system (Age 6+)	<ul style="list-style-type: none"> <li>• They wanted to send me back to S clinic. I said "<u>Do not bother sending me to that one</u>".</li> </ul>
	<ul style="list-style-type: none"> <li>• We <u>went through four child-minders</u> before he found a suitable one.</li> </ul>
	<ul style="list-style-type: none"> <li>• People just <u>couldn't cope with him.</u></li> </ul>

<b>Chapter 7:</b> Transition primary – secondary (9-11 years)	<ul style="list-style-type: none"> <li>At that point, <u>he hadn't needed, we hadn't needed</u> any formal paperwork because where he went to school <u>they supported him extremely well</u> in that aspect.</li> <li>Year 6 we <u>needed a formal diagnosis...</u> we sort of needed a formal one <u>to get him through...</u></li> </ul>
<b>My Interpretation and Commentary</b> ( <i>What is the impact of the later diagnosis?</i> )	
<ul style="list-style-type: none"> <li>Maria expressed <u>early and severe concerns</u> about Kyle's development and the challenges of coping with his behaviour, using the imperative 'imagine...' to invite me to visualise and understand her experience. Maria used the speed of professional involvement to validate her early concerns and her perception of Kyle's high level of need. She later further verified Kyle's challenging behaviour, by describing difficulties in finding a childminder who could "manage him". Maria disclosed that she experienced a "<u>breakdown</u>", which signified the negative impact of parenting a child with undiagnosed ASC. Maria used imperatives to emphasise how previous 'support' was not perceived to be supportive, "do not bother sending me..." Perhaps this was due to the focus on 'parenting skills' rather than being tailored to ASC specific parenting support.</li> <li>Maria described her <u>lack of explanation</u> for Kyle's behaviour: "we didn't know what it was" and the potential impact on her family planning decisions.</li> <li>Maria repeated her sense of feeling <u>blamed</u> and <u>judged</u> when she asked for help. She described the health visitor team as "hopeless" and not "much help at all". Maria reported feeling like she wasn't believed or taken seriously, and that professionals dismissed her concerns, directly quoting them: "oh no that's not a problem". Furthermore, Maria recounted the time that school staff misunderstood Kyle's sensory issues as a social care issue. [REDACTED]</li> <li>Maria shared her emotional response: "really angry", "upset", "disappointed" and "let down". She used comparators to suggest that things <u>would have "made more sense"</u> and "<u>been a lot easier</u>": <u>an earlier diagnosis may have led to improved understanding and/or additional support.</u></li> <li>Finally, Maria described her <u>perceived 'need' for diagnosis</u> during the transition to secondary school, and wanting it to "be formal" and "on paper". She believed that the diagnosis would be required to "get him through" secondary school.</li> </ul>	

Table 25: Maria's experience narrative: Diagnosis phase

Timescales	Maria's Experience Narrative
<b>Chapter 8:</b> Diagnosis, useless doctors (10-12 years)	<ul style="list-style-type: none"> <li>From [age] 10 to 12... that's <u>how long it took us to get the diagnosis.</u></li> <li>Diagnosis and <u>incompetency</u> I think is ... or shall I say <u>useless, useless</u> doctors. He was my <u>biggest bane of my life.</u></li> <li>We were <u>really badly let down</u> by this gentleman... I <u>ripped hell out of him.</u></li> <li>He had met our SENCO at that point and <u>she found him arrogant...</u> He was just <u>a nightmare.</u></li> </ul>

	<ul style="list-style-type: none"> <li>• <i>So basically a feeling of <u>anger</u> at him that he thought he was <u>mightier than God</u> [and] that <u>everyone else should do the paperwork</u>.</i></li> <li>• <i>I have been through it with two people and the third person is asking me the same information, <u>like a broken record</u>.</i></li> <li>• <i>All he had sent was an A4 sheet every time it had gone to panel, so <u>how can anyone do a diagnosis from that?</u></i></li> <li>• <i><u>That really narked me</u>.</i></li> <li>• <i>So as a result, I had to do all the <u>paperwork</u>, <u>run around all the paperwork</u>... <u>It did feel like I was in a tornado</u>.</i></li> <li>• <i>The only way you get anything done is <u>by you taking the lead</u> and go right – this needs to be done.</i></li> <li>• <i>It was the <u>anger</u>, the fact that I had gone through <u>7 months</u> and nothing had been achieved whatsoever and <u>I know these processes take so long</u>, I am prepared for that, but <u>nothing has been done</u> and it has taken me one meeting... a couple of days to get all his paperwork together... and <u>within a week</u>, I had got him diagnosed.</i></li> <li>• <i>It was just <u>he was messing around</u> and that was <u>pure anger</u>.</i></li> </ul>
<b>Key turning point:</b> Diagnosis of autism	<ul style="list-style-type: none"> <li>• <i>(Sigh) <u>Gratification</u>... that it was confirmed that I was right. I <u>knew what it was</u> and that <u>at least I had a piece of paper</u> that if anyone turned round and said, “what is his diagnosis?”, I could turn round and say <u>he is definitely on the autistic spectrum</u>, he has got traits of ADHD and he is dyspraxic.</i></li> </ul>
<b>My Interpretation and Commentary</b> ( <i>What is the impact of the later diagnosis?</i> )	
<ul style="list-style-type: none"> <li>• Maria implied that the time to “get” the diagnosis was <u>too long</u>. She repeated the time frame ‘7 months’, which served to emphasise the waiting time. She acknowledged that “these processes” can be lengthy, but she recalled her realisation that “nothing ha[d] been done” and expressed her frustration as “anger” and feeling “narked”, with particular reference to repeating the same information several times. Throughout, Maria used lexical repetition of her emotion, ‘anger’, as well as adding intensifiers ‘really angry’ and ‘pure anger’.</li> <li>• Maria described the paediatrician with powerful adjectives, “incompetent”, “useless”, “a nightmare” and used the superlative “biggest bane of my life”. She validated her view by reporting that the SENCO also found him “arrogant”. Maria shared her perception that he thought “everyone else should do the paperwork”. Maria described that this experience left her <u>feeling “angry” and “badly let down”</u>. She recounted her actions that she “ripped hell out of him”. In response to the lack of information shared by the doctor, her question, ‘how can anyone do a diagnosis from that?’ served to further highlight her <u>frustration</u>.</li> <li>• At this point, Maria positioned herself as <u>taking the lead</u> in collating all the paperwork, and <u>pro-actively co-ordinating professionals and information-sharing</u>. There was a sense of going round in circles, which Maria described figuratively, “like I was in a tornado”. At the resolution of this narrative episode, Maria contrasted the earlier lengthy time frames: “within a week, I had got him diagnosed”. The later recognition and referral in conjunction with the timing of the primary-secondary school transition, may have created a <u>greater sense of urgency</u> for Maria. Alternatively, her pro-active approach may have resulted from her feeling “let down” by professionals regardless of the timing.</li> </ul>	

- Maria described receiving the diagnosis of autism as the key turning point. She described her “gratification” when the diagnosis was confirmed that she had been right. I interpreted that she seemed reassured by receiving the ‘formal diagnosis’, both in terms of her own understanding, “I knew what it was”, as well as to explain Kyle’s needs to others, “at least I had a piece of paper”.

Table 26: Maria’s experience narrative: Post-diagnosis and general reflections throughout the interview

Timescales	Maria’s Experience Narrative
<b>Chapter 9:</b> Breakdown level, problem behaviour (13 years)	<ul style="list-style-type: none"> <li>• That would come down to <u>breakdown level</u>. We had problems with stealing, behaviour <u>causing major upsets</u>.</li> <li>• I was having meetings at the school <u>and I broke down in tears... I had just had enough</u>.</li> <li>• The only way we did it by... was getting proper help with [EP] dealing with him, because <u>he diagnosed him, he dealt with the school...</u> and I was meeting [him] here on a weekly or monthly basis... [EP] is my angel, literally.</li> </ul>
<b>Nadir experience:</b> Too much to handle(13 years)	<ul style="list-style-type: none"> <li>• Because that was <u>dealing with</u> obviously the cancer, <u>dealing with</u> my husband and everything else and the little one.</li> <li>• <u>Too much to handle</u>.</li> <li>• Dealing with behaviour, <u>still working</u> and <u>still running round</u> and <u>still doing everything else</u>.</li> </ul>
<b>Theme</b>	<ul style="list-style-type: none"> <li>• Being a <u>bulldog</u> [laughs]. My son would call me a bulldog because I need to get something done... Yeah, <u>stubborn bulldog</u>.</li> <li>• I have literally <u>fought tooth and nail over most things</u>.</li> </ul>
<b>Title</b>	<ul style="list-style-type: none"> <li>• ‘<u>Endurance</u>.’ Endurance of the third kind... because you just can’t give up at any point.</li> <li>• It’s mental ability. It is a mental thing, it is not a physical thing.</li> <li>• You can have moments where you think “<u>Can I really do this?</u>”</li> <li>• You have got to do such short steps so it is <u>an endurance process</u>, it is <u>like running a marathon</u> mostly.</li> </ul>
<b>General Post-diagnosis Reflections</b> (no particular timescales)	<ul style="list-style-type: none"> <li>• [Kyle] could be a very good mountain climber when he is older because he has been down... <u>every pothole</u> and he will come back up.</li> <li>• The trouble with having to parent with a child with any disability, is <u>you become horrible!</u> [laughs] Because you have to <u>fight for every single thing...</u> people will tell you that [they’re] doing things, especially when it comes to referrals, and <u>they don’t do them</u>.</li> </ul>

**My Interpretation and Commentary** (*What is the impact of the later diagnosis?*)

- Maria described this time as “breakdown level”, reporting her sudden emotional breakdown at school. From her description of her actions, “I broke down in tears” and I interpreted her perceived vulnerability and sense of feeling out of control. Maria seemed to have reached a crisis point: “I had just had enough”. At this point, she received 1:1 help from the EP to support with behaviour strategies. In contrast to previous lexical terms, “nightmare” and “bane of my life”, Maria describes the EP as “her angel”.
- Maria described this as the worst time overall. Despite her earlier comments that the ‘not knowing’ was a source of stress, Maria did not indicate that this was reduced after the diagnosis, perhaps due to other arising stressors (loss, another child and new behavioural challenges with Kyle).
- Maria expressed the cynical view that ‘people’ (referring to professionals) don’t do things, particularly referrals. She used the language of having “to fight” and jokingly described the effect of this on her own identity, “you become horrible!”
- Maria used metaphor to explain her perception that Kyle tends to hit every pothole (problem or hurdle), but that he tends to “come back up” (recover). Staying with this metaphor, I interpreted that Maria believes that her ‘journey’ had been a ‘bumpy ride’ and an “endurance process”. This was consistent with Maria’s chosen title, ‘endurance’, which she explained captured her perception of not giving up, despite questioning her own ability.

### 5.3.2. Cathy and Jake: Research Question Two

In Tables 27-19, I present and discuss Cathy's narrative of her experiences, and conclude that Cathy's pre-diagnostic experiences were very different from Maria's: in Jake's early years, Cathy expressed little or no concern, most likely due to his subtle presentation. When Jake was diagnosed with Tourette's syndrome (aged 6-8 years), Cathy seemed to express more curiosity than concern. During Jake's adolescence (aged 13-15), Cathy expressed severe concerns about his behaviour, describing this phase as "a traumatic time", worsened by lack of understanding from others about Jake's 'hidden' difficulties. Cathy indicated that a *slightly* earlier diagnosis could have led to improved understanding, help and advice, leading to better preparation for adolescence and reduced parental distress.

During the 'realisation' phase, immediately preceding the referral and diagnosis, Cathy expressed gratitude that her concerns were understood by secondary school staff (Jake was 15-16 years). She also expressed anxiety, uncertainty and hopelessness that it might have been too late to get help. Due to his impending 16<sup>th</sup> birthday, seeking Jake's consent was considered a possible barrier to diagnosis and support for parents, leading to fear, desperation and powerlessness.

Cathy was disappointed with the waiting time (2 months) and expressed frustration, disappointment and disbelief that the initial appointment was considered "wasted". This created further uncertainty, but following referral to the diagnostic panel, the process itself was considered "very straightforward".

Post-diagnosis, Cathy considered that the situation improved for Jake and his parents, reducing their worry and increasing their understanding. Cathy described the positive impact for Jake on his self-awareness and understanding: the later timing may have benefitted Jake, due to his maturity. Cathy noted feelings of regret and guilt and reflects on the 'chance' element. Finally, Cathy considered that

an earlier diagnosis may have been less traumatic, but at no point suggested a need or desire for ASC to have been identified any earlier than 6-8 years.



Table 27: Cathy's experience narrative: Pre-diagnosis

Timescales	Cathy's Experience Narrative
<b>Chapter 2:</b> Early years (<2.5 years)	<ul style="list-style-type: none"> <li>• He was a comical toddler, he did comical things, but that was just him... <u>it wasn't anything that alarmed me at the time.</u></li> <li>• Things when he was little which I'd noticed, but <u>never thought nothing of.</u></li> </ul>
<b>Chapter 4:</b> Primary Years: Infants (4-8 years)	<ul style="list-style-type: none"> <li>• He was 8 when I took him to the opticians because the habits started.</li> <li>• [Other parents] say, "Oh mine blinks their eyes... it is nothing to worry about", so <u>you just accept that for a while.</u></li> <li>• That became quite <u>annoying [laughing] and worrying</u> because you think "well, <u>why is he doing it?"</u></li> <li>• They just listened to what I said and <u>sent us away.</u></li> <li>• <u>I don't think there are definite answers</u> to a lot of these questions because I still think <u>it is still being researched</u></li> </ul>
<b>Chapter 7:</b> A traumatic time (13-15 years)	<ul style="list-style-type: none"> <li>• From 13 to 15, we started hitting a lot of <u>problems</u>. We had a lot of <u>battles</u> going on... a lot of <u>arguments</u> about his attitude.</li> <li>• It was <u>getting worse</u> and he was <u>getting bigger</u>.</li> <li>• You'd be like (sighs)... it was a <u>really, really difficult</u> time... It was <u>really, really hard</u>.</li> <li>• We kind of <u>had enough</u> of it... I used to be like "<u>Aagh</u>"!</li> <li>• <u>Traumatic</u> to me (laughs). Oh! ... And I think Jake, it must have been <u>traumatic</u> for him as well.</li> <li>• That was a <u>horrendous</u> night, the night he did that [ran away]...</li> <li>• Every time we tried to tell other parents or like friends... it doesn't come across how bad it was.</li> <li>• ...people would say, "Well, he is just a teenager and yeah, ours are the same"... but then there would be another occurrence.</li> <li>• His [biological] Dad and [I] completely fell out over it. Because they don't see our point of view.... They don't really see the problems.</li> <li>• It was just a <u>nightmare</u>... me and my husband fell out, he ran away a couple of times when he was about 12 or 13.</li> <li>• Things were very much <u>strained</u> between me and my husband... how Jake was took its <u>strain</u> on us as a family.</li> <li>• We couldn't deal with it, but <u>we didn't know what we were dealing with</u>. Which again, <u>if we had been diagnosed at a younger age, we would have been prepared</u>. <u>We could have got help and advice at the time, but we didn't have a clue</u>. We just thought he was rebelling, he was rebellious towards us. <u>We just couldn't deal with it.</u></li> </ul>

<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	<ul style="list-style-type: none"> <li>• <i>That [Jake's lack of reaction to dog dying] <u>upset</u> us, because we were <u>devastated</u> by it and again, in my mind, you are thinking, "well, I have reared a monster?"</i></li> <li>• <i>I was <u>really worried</u> about him, about his state of mind.</i></li> <li>• <i>I was <u>frightened</u> to look at him sometimes... he seemed depressed to me and, as a parent, that is <u>quite worrying</u>... <u>You just don't know what is going on</u>... and it was <u>quite stressful</u> again at that time.</i></li> </ul>
<b>Nadir experience</b>	<ul style="list-style-type: none"> <li>• <i>We had already gone through <u>2 years of trauma</u>. I realised what it was, but <u>didn't know what I'd got to do about it</u>.</i></li> <li>• <i>I was <u>on anti-depressants</u> myself for that year.... It was <u>a really tough time for all of us</u>.</i></li> </ul>
<b>My Interpretation and Commentary</b> ( <i>What is the impact of the later diagnosis?</i> )	
<ul style="list-style-type: none"> <li>• In Jake's early years, Cathy noted some unusual interests, but was <u>not concerned</u> and normalised his "comical ways". A referral or diagnosis at this stage seemed <u>unlikely to have been necessary or helpful</u>. Furthermore, these differences were unlikely to have been <u>sufficient to warrant a diagnosis</u>, due to Jake's high level of functioning and low/no need for support, in line with DSM-5 criteria (Table 1).</li> <li>• Cathy seemed <u>matter-of-fact</u> about the diagnosis of Tourette's syndrome. She laughed that Jake's behaviours were "annoying" and indicated more curiosity <u>than concern</u> at this stage. Cathy appeared <u>dissatisfied with the lack of support</u> offered following the diagnosis of Tourette's syndrome and reflected on the <u>uncertainty</u>, even from professionals, around the validity of this diagnosis with the hindsight of the ASC diagnosis.</li> <li>• Later, when Jake was 13-15, Cathy recalled behavioural challenges and "family issues", describing this as "<u>a traumatic time</u>". She used the lexical repetition of "problems", "arguments" and "battles", as well as adjectives "difficult", "horrendous" and "traumatic", and intensified this with really, really". She also quoted herself as sighing "aagh" and even saying that they'd "had enough", from which, I infer a sense of build-up to crisis point. Cathy described this period as "<u>a nightmare</u>" and used the lexical repetition of "<u>strain</u>" to describe the negative effect of Jake's behaviour on family dynamics.</li> <li>• Cathy seemed <u>frustrated</u> that others (friends and family) didn't understand their difficulties or 'see' the problems.</li> <li>• Cathy and her husband were <u>upset</u> by Jake's differences in emotional processing, empathy and reading social cues, which were, at the time, unexplained, demonstrated by her dramatic question, "Have I reared a monster?" This highlighted the impact for Cathy of living with the challenges of ASC, <u>without the diagnostic label to understand</u>. I interpreted that an <u>earlier diagnosis may have led to improved understanding and reduced parental distress</u>.</li> <li>• Cathy's nadir experience (worst moment) was "two years of trauma" preceding the realisation and diagnosis. Cathy disclosed that she was on anti-depressants, which illustrated the impact upon her own mental health at the time.</li> <li>• Cathy suggested that an earlier diagnosis may have led to better preparation for adolescence and "help and advice" during this traumatic time.</li> </ul>	

Table 28: Cathy's experience narrative: Diagnosis phase

Timescales	Cathy's Experience Narrative
<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	<ul style="list-style-type: none"> <li>• <i>[The school liaison officer said] "is this what he is like back at home? ...I don't know how you put up with him"</i></li> <li>• <i>[The SENCO and liaison officer] actually listened and understood for the first time... you just sometimes need someone to... understand.</i></li> <li>• <i>[When I found Asperger's on the internet] I couldn't believe it. Because I felt as though somebody must have written it about my son and about my life, there was <u>everything</u> there, absolutely <u>everything</u>. It described the feelings that we were going through, things when he was little which I'd noticed, but <u>never thought nothing of</u>.</i></li> <li>• <i><u>What do I do?</u> Somebody who is 1 month off 16... <u>How do you deal with that?</u> That <u>wasn't an easy time at all</u>.</i></li> <li>• <i>Once he turns 16, it [referral] has to be with his consent... you <u>lose all control</u> at that age.</i></li> <li>• <i>If he had said, "no I'm not going", there <u>wouldn't have been a damned thing I could do</u> about it.</i></li> <li>• <i>Jake was under the impression that it was to do with family issues... <u>but I knew it was because we thought he had got Asperger's</u>.</i></li> <li>• <i>I was <u>gutted</u>. Because you just want it done yesterday (laughs)... we couldn't go until the April, so <u>we had to wait</u>.</i></li> <li>• <i>I <u>probably did cry</u> when I got that letter. I was like, "<u>oh no</u>", because I want to go now, not wait.</i></li> <li>• <i>I was so <u>disheartened</u> because <u>at the age of 16, what chance do they have of proving it or having some answers or having any help?</u></i></li> <li>• <i>[At initial appointment] I was thinking, "<u>I don't believe this...</u>" We have half an hour, we have spoken about <u>stupid details which aren't anything to do with the problem</u> and we have talked for 15 minutes and to turn around and say, "<u>Oh I don't think...</u>"</i></li> <li>• <i>I was really <u>disappointed and upset</u>, and I thought "I've waited from January to April for nothing"</i></li> <li>• <i>We went to see the autism diagnostic team... and it was all very <u>straightforward</u>.</i></li> <li>• <i>Looking back now, you think, "yeah, it didn't take that long at all", but it didn't feel like it at the time.</i></li> <li>• <i>You read on the internet other families who have <u>gone through it for years</u> and they haven't had a diagnosis, so <u>they have been fighting</u>, trying to prove to professionals for years.</i></li> <li>• <i><u>As traumatic as it was, that was pretty good really</u> in comparison to what, I am sure, a lot of other people's stories are.</i></li> </ul>
<b>My Interpretation and Commentary</b> (What is the impact of the later diagnosis?)	
<ul style="list-style-type: none"> <li>• Cathy narrated interpretative remarks made by school staff, which served to <u>vindicate</u> Cathy's descriptions of the family's difficulties. This marked 'a realisation' for school staff about the extent of <u>Jake's hidden difficulties</u>. This seemed to be the first time that a professional has "seen", "listened" and "understood" Cathy's concerns and she appeared <u>grateful</u>.</li> </ul>	

- Upon ‘finding’ autism and Asperger’s syndrome on the internet, Cathy explained that this was the first time she could “relate to” others’ experiences. She expressed disbelief at the discovery of Asperger’s syndrome, followed by her uncertainty, illustrated by her repetitive questions, “How do you deal with that?” Cathy made direct reference to Jake’s age (16 years at the time) emphasising her sense of uncertainty and/or hopelessness.
- Cathy expressed a sense of fear, desperation and powerlessness, about Jake consenting to the ASC referral: “you lose all control at that age”. She appeared anxious that if Jake did not consent, this may have formed a barrier to support for the family and securing an explanation, or that it might have been too late to help him or the family situation.
- Cathy expressed frustration and disbelief that, after a perceived lengthy wait (two months), the appointment seemed wasted, due to her recollection that the social worker, who led the appointment, dismissed the idea of ASC, without understanding their problems. Cathy was left feeling “disappointed” and “upset” and expressed a lingering sense of uncertainty: “I just didn’t know where we were going to go”.
- Cathy described the process as “very straightforward” and seemed matter-of-fact and unemotional about the diagnosis itself, perhaps because the earlier ‘realisation’ evoked more of an emotional response. Cathy contrasted the longer waiting times of other parents (on the internet) and concluded that, despite the “trauma” experienced, her overall experience was “pretty good really”.

Table 29: Cathy’ experience narrative: Post-diagnosis and general reflections throughout the interview

Timescales	Cathy’s Experience Narrative
<b>Chapter 1:</b> Special baby (pregnancy)	<ul style="list-style-type: none"> <li>• <i>I felt like I was accused of being a bad mother and I really wasn’t because he was special, he was special from the start.</i></li> </ul>
<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	<ul style="list-style-type: none"> <li>• <i>[Things are] much better, I think.</i></li> <li>• <i>We have tried to be <u>more understanding</u>. We are not so worried now... we know what it is.</i></li> <li>• <i>He makes <u>jokes about it</u>, whereas in the past... he <u>would have been nasty and aggressive</u>.</i></li> <li>• <i>He will sometimes go on about something and then <u>he realises he is doing it...</u> and then he’ll say, “Ooh, <u>you know what I’m like</u>”</i></li> <li>• <i>Whereas in the past... it would <u>turn into an argument</u>.</i></li> <li>• <i>Again from what I’ve read, <u>the hormonal stage</u> is bad for a lot of teenagers, but with autism or Asperger’s, it is very different again... and I can relate to that now.</i></li> <li>• <i>Jake knowing what it is [has] helped him a lot... think he <u>understands himself better</u>.</i></li> <li>• <i>He then even mentioned things to me that he did that I wasn’t aware of, but he was aware of but <u>didn’t know why he did them</u>. It then <u>made sense to him</u> and he even spoke about <u>like a weight was lifted off his shoulders</u>.</i></li> </ul>

	<ul style="list-style-type: none"> <li>• <i>[He said that] he always <u>felt sort of odd around other kids</u> and different. He had <u>never been able to understand why</u>, so if anything, I think <u>it has helped him tremendously</u>.</i></li> <li>• <i><u>Though it was later than I would have liked</u>, at that point, they [SENCO and liaison officer] made me realise what was going on.</i></li> </ul>
<b>Chapter 9: Moving forward (17 years+)</b>	<ul style="list-style-type: none"> <li>• <i>I think [Jake] <u>understands himself better</u>.</i></li> <li>• <i>He is <u>more settled</u> in himself which obviously <u>makes us happier as well</u> (laughs).</i></li> </ul>
<b>Peak experience</b>	<ul style="list-style-type: none"> <li>• <i>I suppose the best was the point we are at now... because <u>Jake is happier and he is doing well</u>... We are <u>a lot happier as a family</u>.</i></li> </ul>
<b>General Post-diagnosis Reflections</b> (no particular timescales)	<ul style="list-style-type: none"> <li>• <i>It is <u>fascinating</u> looking back at last year when we went through the diagnosis... and thinking “I am his Mum, why didn’t I know?”</i></li> <li>• <i>Then <u>obviously you have got the regrets</u>... thinking “Oh, why didn’t I do anything?”</i></li> <li>• <i>It <u>would have been so easy</u> for Jake to have gone to live with his dad, ended up staying there, <u>but it wouldn’t have been the right thing for him</u>. Me and my husband would have ended up <u>splitting up which wouldn’t have been the right thing for us</u> and that <u>would have been it; the whole family would have been split apart</u>. <u>It would have been so easy... We may never have known</u>.</i></li> <li>• <i>When we did finally get to see the social worker... it <u>would have been so easy to have just walked out</u>.</i></li> <li>• <i>We got to the age of Jake being 16 and never been picked up, and <u>if it hadn’t have been picked up then... [it] was just by chance, it was a fluke really</u>...</i></li> <li>• <i>If it had have been picked up earlier, <u>it would certainly have been a lot less traumatic</u>.</i></li> <li>• <i>If there was more awareness, <u>we probably wouldn’t have gone through this</u>.</i></li> <li>• <i>It came good in the end, however difficult this year was.</i></li> </ul>
<b>My Interpretation and Commentary</b> ( <i>What is the impact of the later diagnosis?</i> )	
<ul style="list-style-type: none"> <li>• Cathy seemed to express a sense of <u>vindication</u> that she was not to blame for Jake’s later behavioural difficulties, as Jake was always ‘special’.</li> <li>• Cathy indicated that <u>things are much better post-diagnosis</u>, due to new levels of understanding for both Jake and his parents. She described Jake being “more settled” and the positive ripple effect for her and her husband. This marked the ‘high point’ of Cathy’s story.</li> <li>• Cathy used comparators to illustrate how things were worse prior to the diagnosis, including arguments, ‘nastiness and aggression’, and her sense that he was “driving her mad”. By contrast, she felt <u>less worried</u>, and described <u>joking</u> and <u>using humour</u> to diffuse previously difficult situations.</li> <li>• Cathy described the <u>potentially disastrous consequences</u> for Jake and the family if the ASC hadn’t been recognised at all: Jake remaining with his Dad/Nan, and Cathy and her husband splitting up.</li> <li>• Cathy read about the challenges and differences of ASC (particularly the influence of hormones at adolescence). She noted that she was <u>able to relate to it</u>, which significantly <u>contrasts with her previous narrative that no-one understood her family’s difficulties</u>. The diagnosis appears to have been <u>helpful</u> for Cathy in this sense.</li> </ul>	

- Cathy described the positive impact of the diagnosis for Jake on his self-awareness and understanding, emphasised by her adverb ‘tremendously’. With hindsight, he was also able to understand his previous sense of ‘being different’.
- Cathy described a “fascination” with the whole experience, as well as a sense of “regret” and possibly guilt that, even though she was his mum, she didn’t notice or act sooner. In my interpretation, Cathy’s post-diagnosis emotions seemed to be linked to her earlier absence of concerns (which may be explained by Jake’s mild ASC presentation, rather than any omission on Cathy’s part). The timing of Jake’s later diagnosis may have led to an increased sense of guilt and regret, although Cathy did not explicitly indicate this.
- Cathy attributed the whole process to “chance” and “a fluke”, which I interpret to indicate her sense of her helplessness and lack of control. She repeated that it would’ve been easy to miss the ASC completely, even following the realisation and referral. She used the powerful comparator, “we may never have known” to accentuate the preferred outcome that ASC was identified.
- Overall, Cathy stated that the realisation (and diagnosis) occurred “later than she would have liked”. She concluded that an earlier diagnosis would have made the situation “a lot less traumatic”. She doesn’t specify how much earlier, although previously she indicated that primary school “could” and the hospital “should” have ‘picked it up’. Interestingly, at no point does Cathy express the need or her desire for ASC to have been identified any earlier than this (before age 6-8 years).

## **5.4 Discussion of findings for RQ2**

The literature reviewed in Chapter Two suggests that later diagnosis of ASC has been associated with lower parental satisfaction with the diagnostic process (Howlin and Moore, 1997; Sansosti et al, 2012) and higher parental stress (Sweeney-Gray, 2013). These positivist measures lack in-depth understanding of parents' experiences. Although research has explored parental experiences before, during and after the diagnosis, no existing research has explored how these experiences may be affected by later AOD. RQ2 sought to address this, and I now discuss these findings in relation to existing research, organised temporally by pre-, during and post- diagnostic experiences, as well as participants' overall reflections about the later diagnosis.

### *5.4.1 Pre-diagnosis experiences*

Existing research suggests that parents' pre-diagnostic experiences are highly varied, supported by the dissimilar stories of the current study. The NAPC (2003) guidance suggests variation in parental recognition of problems. Consequently, parental concern (if any) preceding the diagnosis is highly varied (Braiden et al, 2010), which can be categorised as 'no concern', 'passive concern' or 'active concern' (Ryan and Salisbury, 2012). Maria expressed a high level of (active) concern about Jake's behaviour from a young age, and actively sought an explanation and support. McCaffrey (2011) suggests that parents who actively seek explanation may experience more anxiety and frustration, which certainly appeared to be the case for Maria. In my interpretation, Kyle's later diagnosis may have led to prolonged negative experiences for Maria preceding the diagnosis.

Conversely, Cathy, expressed 'no concern' in Jake's early years, although she began to express a mild level of 'active concern' during the diagnosis of Tourette's syndrome. She later expressed heightened

distress and more 'active concern' due to Jake's emerging behavioural presentation aged 13-15 years. Cathy's absence of concern in Jake's early years raises interesting questions about whether an earlier diagnosis would have been possible and/or necessary, as well as whether the claimed benefits of early diagnosis (Chapter 1) would have outweighed potential disadvantages of diagnosis, such shock and distress (NICE, 2011), and those outlined by Lauchlan and Boyle (2007), including stigmatisation, reduced expectations and social exclusion.

Furthermore, despite NICE guidance (2011) that parental concerns should not be dismissed, the existing literature indicated that this is not always followed in practice, and suggested that professional dismissal and premature reassurance can lead to parents feeling isolated and alone (Ryan and Salisbury, 2012) and lower satisfaction with the diagnostic process (Braiden et al, 2010). Dismissal and false reassurances were experienced by both Maria and Cathy. Maria described feeling blamed for Kyle's behaviour by health visitors and the social care team and felt that she wasn't listened to. Later, Maria reported that another professional dismissed her concerns after a brief 20-minute observation. I interpret that these experiences, in conjunction with Maria's active concerns, contributed to her overall feelings of frustration and anger. Again, as a result of the later diagnosis, Maria's experiences of dismissal spanned a longer period (preceding Kyle's diagnosis); I consider that earlier accurate recognition of ASC may have prevented or reduced this.

Similarly, Cathy felt dismissed by the doctor who diagnosed Tourette's syndrome and later by the social worker who discounted Asperger's syndrome on the grounds of his conversational ability. Her sense of dismissal may have been exacerbated by friends normalising his behaviours. I interpret that Cathy's experience of dismissal was related to Jake's subtle presentation and the 'hidden difficulties'. This suggests that parents of CYP with more subtle symptoms may be more vulnerable to professional dismissal and further highlights the importance of developing professional knowledge and awareness



of more subtle presentation of ASC. Furthermore, this also highlights the need for professionals to be aware of limits to their own knowledge and knowing when to refer to other professional agencies (Health and Care Professions Council, 2012)<sup>10</sup>.

#### *5.4.2 Experiences of the diagnostic period*

Existing evidence suggests that parental experiences of the diagnostic period are highly varied (Braiden et al, 2010), which is supported by the current study. Maria reported feelings of anger, frustration and feeling “let down”, due to her perception of poor information-sharing, repeating information and seemingly unnecessary delays between meetings, which is commonly evidenced in existing research, suggesting that it can be a stressful, distressing, frustrating time (Keenan et al, 2010; Rose, 2011). Cathy, conversely, described the diagnostic process itself as “very straightforward”. This finding supports Braiden et al’s (2010) finding that parental experiences of the diagnostic process are highly varied, regardless of the timing of the diagnosis.

Current findings also highlight that the diagnostic process itself may not be the most (emotionally) significant event or experience for parents, despite existing evidence that the diagnosis itself is considered a highly significant event for parents (Slator, 2012) and is often the key turning point in parents’ online narratives (Fleischmann, 2004). I positioned ‘receiving a later diagnosis of ASC’ as the plot, which undoubtedly increased the significance of this event in parents’ narratives. In Maria’s narrative, confirmation of the diagnosis *was* the key turning point. Interestingly, however, Cathy described the key turning point as her realisation, rather than confirmation of the diagnosis, suggesting that for some parents, the realisation may be a more significant experience than the diagnosis itself.

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<sup>10</sup> Standard Six: “act within the limits of your knowledge, skills and experience and, if necessary, refer the matter to another practitioner” (HCPC, 2012, p. 3).

This is linked to Fleischmann's (2004) finding that the turning point is often the moment that parents recognise the child's ASC. This further highlights the need for timely and appropriate parental support.

Cathy expressed anxiety and powerlessness about seeking Jake's consent to the ASC referral, which could have formed a barrier to securing an explanation and support for the family. This raises important implications for practice (Section 5.5).

Furthermore, findings of the current study suggest that parental concern fluctuates across the CYP's development, before and after diagnosis, contingent on presenting issues and challenges. The nadir experience (worst moment) for both Maria and Cathy related to periods of challenging behaviour. For Cathy this period occurred immediately preceding Jake's diagnosis and was, in my interpretation, the catalyst for seeking support initially (family therapy), rather than an explanation. For Maria, interestingly, Kyle's 'spike' in behaviour occurred after the diagnosis (although unrelated to the diagnosis). Consistent with existing research (McStay, 2014; Teehee et al, 2009; Molina, 2014), this highlights the everyday challenges of living with a child with ASC, particularly in relation to coping with behavioural challenges, regardless of the timing of the diagnosis. This is consistent with Osborne et al's (2008) finding that confirmation of the diagnosis did not change parenting stress in either direction. From this, it seems that parents may place high value on receiving *support* contingent to their concerns at the time, as well as the *diagnosis* itself.

In existing research, the duration of the diagnostic period predicted parental satisfaction: longer waiting times were associated with lower parental satisfaction (Howlin and Moore, 1997) and many parents considered the diagnostic process to be too long (Keenan et al, 2010; Glazzard and Overall, 2012). Interestingly, both Maria and Cathy reported a *perception* that the diagnostic process was too long, despite the disparity in duration (Maria: 2 years; Cathy: 2-3 months). Cathy acknowledged that

despite a relatively short and reasonable waiting time of 2 months for the initial appointment, she felt “gutted”. In Cathy’s case the referral was also for family therapy, suggesting that her sense of urgency related more to accessing support, contingent on her contemporaneous level of distress.

Findings of the current study suggest that shorter waiting times and timely diagnosis *and support* are preferable for parents, contrary to Osborne et al’s (2008) surprising finding that shorter timescales between noticing concerns and receiving the diagnosis were associated with higher levels of parenting stress. This has implications for improving parents’ experiences of the diagnostic period (Section 5.5).

#### *5.4.3 Post-diagnosis experiences*

Existing literature described emotion-focused and task-focused parental reactions to the diagnosis. Firstly, receiving the diagnosis is considered a time of emotional upheaval for parents (DCSF, 2010; Abbott, 2012), and a variety of mixed emotions may be experienced, including grief, anger, denial, guilt, shock, disbelief, stress, depression and relief (Abbott et al, 2012; Casey et al, 2012; Fleischmann, 2004; Mansell and Morris, 2004; Mason, 2012; Midence and O’Neill, 1999; Molina, 2014; Taylor and Warren, 2012; Slator, 2012; Stuart and McGrew, 2009).

Interestingly, parents in the current study did not dwell on their immediate emotional reaction to the diagnosis. When I asked Maria how she felt upon receiving the diagnosis, she described her gratification and relief, consistent with existing research findings (Abbott et al, 2012; Fleischmann, 2004; Mansell and Morris, 2004; Midence and O’Neill, 1999; Molina, 2014). Although Cathy gave no indication of her initial emotional reaction to the diagnosis, she reflected upon the impact of her realisation (before the diagnosis). She expressed disbelief, as well as gratitude that school staff had understood her concerns, and a sense of regret and guilt that she had not known. This is consistent

with parental feelings of shock noted by Glazzard and Overall (2012), NICE (2011) and DCSF (2010), and guilt suggested by DCSF (2010). I interpret that Cathy's earlier absence of concerns and the later timing of the realisation may have contributed to her feelings of regret and guilt, although Cathy did not explicitly indicate this. The current study supports evidence of mixed emotions, but there is no clear conclusion about the influence of the later timing in either case: further discussion with participants would have been necessary.

Secondly, the task-focused response to diagnosis includes the search for information and support (Mansell and Morris, 2004; McCaffrey, 2011). Previous research indicates that post-diagnostic support is perceived to be poor (Howlin and Moore, 1997), and some parents report that insufficient advice is given (Keenan et al, 2010), but these experiences vary (Braiden et al, 2010; Boorn, 2010). Neither Maria nor Cathy discussed post diagnostic support in detail. Maria only briefly mentioned the value of behaviour support provided by the EP, which seemed contingent on Kyle's escalation in behavioural dysregulation at the time, rather than as a result of the diagnosis itself. Cathy also omitted to describe any support and advice (if any) that was offered or received, despite having initially sought family therapy. It is unclear from her story whether this therapeutic work took place and it seemed that Cathy portrayed the diagnosis as an end in itself: she noted improvements to her own and Jake's understanding and their ability to manage previously difficult situations.

Good practice guidance suggests that parents should not have to wait for a diagnosis in order to access support (NAPC, 2003; DCSF, 2010). In Cathy's story, this seemed to be put into practice, as the referral for assessment of ASC was made simultaneously with the referral for family therapy. In Maria's case, however, despite early professional involvement, Maria did not perceive proffered support to be helpful, and felt judged. This could be explained by Kyle's needs (and her own) not being understood through the lens of ASC: perhaps the later EP support post-diagnosis was tailored more appropriately

in light of the diagnosis. This has important implications for providing *timely and appropriate* support for parents, regardless of the timing of diagnosis.

#### *5.4.4 Reflections on the later timing of the diagnosis*

Both Maria and Cathy reflected on the potential benefits of an ‘earlier’ diagnosis, through their use of explicit and implicit evaluative devices (‘comparators’ were used to compare events that did not happen with those that did; Labov, 1972; Cortazzi, 1993; Appendix 7). In line with Lauchlan and Boyle’s (2007) suggestion that one advantage of diagnosis is increased understanding of needs, Maria suggested that an earlier diagnosis could have led to improved understanding and/or additional support. Similarly, Cathy suggested that an earlier diagnosis could have led to improved understanding, help and advice, leading to better preparation for adolescence and reduced distress.

I consider, however, that there was disparity in the age at which Maria and Cathy considered that an ‘earlier’ diagnosis would have been most beneficial, in hindsight. In Chapter One, I described the dominant view of many authors in the literature, who (either implicitly or explicitly) suggest ‘the earlier the better’ in their search for the earliest possible detection of ASC (Eaves and Ho, 2004; Kleinman et al, 2008; Lord, 1995; Moore and Goodson, 2003; Stone et al, 1999; Stone et al, 2008). Conversely, however, Matson et al (2008) suggest that there is likely no ‘magic cut-off’ for ‘early’ identification, which is supported by the current study. In Maria’s case, I interpret that the ideal time for a diagnosis would have been during Kyle’s early years (ranging from birth- 5years), arising from her early concerns, multiple professional involvements and her request for support. In Cathy’s case, however, it seemed that she did not indicate a need or desire for an accurate diagnosis any earlier than 6-8 years, when Tourette’s syndrome was diagnosed. Cathy’s use of modal verb comparators illustrated her view that primary school “could” have identified ASC, but the doctor who diagnosed Tourette’s “should” have

explored this possibility. Cathy suggested the most beneficial time for 'earlier' diagnosis would have been at least before Jake's onset of behavioural difficulties (aged 13-15). It seems that the 'ideal age' for diagnosis, as indicated by the parents in this study, may not always be as early as the research suggest is possible and/or desirable (Chapter 1). By considering complete individual stories over time, the current study has added new insights by allowing participants to reflect on this. The perceived ideal of diagnosing 'as early as possible' seems to be a blanket judgement, without recognition of individual circumstances. This tentative conclusion, however, certainly warrants further investigation.

Moreover, although it was not the focus of the current study, Cathy spoke about the significant positive impact of the diagnosis for Jake; through facilitating his improved self-awareness and understanding of his previous sense of 'being different', in hindsight. This raises further questions about the impact of later diagnoses on CYP themselves. In speculating about Jake's case, it is possible that the later diagnosis was beneficial in his being able and mature enough to research ASC on the internet and reflect upon what this meant for him. Conversely, Jake may have benefitted from this information and self-understanding earlier and prior to the family's 'traumatic time'. This highlights a need for further research with CYP.

In exploring parents' perceived 'impact' of the diagnosis and its timing, the current study highlighted interesting parental views about the function and purpose of the diagnosis. Maria reflected on her increased perceived *need* for a diagnosis during Kyle's transition to secondary school. She considered that a formal diagnosis would be necessary for secondary school, with the 'audience' for diagnosis as people outside the family. This highlights that Maria considered that diagnosis would be a gateway to resources, although as Lauchlan and Boyle (2007) point out, this is not always a simple, linear progression.

Cathy, on the other hand, suggested that the diagnosis served to improve understanding of Jake's needs and differences within the immediate family. Again, this preliminary finding has implications for further research to explore the perceived *function* of the diagnosis, and how this varies throughout different ages and stages of the child's development, from the perspective of both parents and/or CYP.

Finally, Maria alluded to the impact of receiving a later diagnosis on her own identity, "you become horrible!" as a result of her perception of 'having to fight' over a lengthy period of time, from her first concerns in Kyle's early years, until his diagnosis at early adolescence. Whilst there is existing general research into the identity of parents with CYP with special educational needs, including autism (for example, see Tessen, 2014 and Lawrence, 2011), and into the everyday challenges of parenting a CYP with autism (Section 2.4.1), this finding highlights scope for further research to specifically explore the impact of receiving a *later* diagnosis of ASC on parent identity.

## **5.5 Implications (RQ2)**

### *5.5.1 Implications for practice*

Findings from RQ2 highlight some general practical implications about parental support before, during and after a diagnosis of ASC, irrespective of the CYP's age at diagnosis. The parents in the current study placed higher value on support offered contingent on their contemporaneous concerns and needs, rather than the diagnosis itself. This is consistent with good practice guidance that parents *should* be able to access support without waiting for a diagnosis (NAPC, 2003; DCSF, 2010). In Cathy's case, this was achieved as family therapy was sought at the same time as an ASC assessment, but in Maria's case

early professional involvement (which focused on her parenting skills) was not perceived as supportive. This highlights the importance of not only the timeliness of support, but also the appropriateness of support. Furthermore, the possible negative impact of later diagnosis on parent identity, as described by Maria, has significant implications for how support packages and interventions may be designed to suit this parent group. However, this finding is only preliminary and parent identity in relation to age of autism diagnosis certainly warrants further research.

Professional dismissal of parental concerns, evident in both stories, suggests that good practice guidance (NICE, 2011) is not always followed in this respect. This needs to be improved in practice and may relate, at least in Jake's case, to professional awareness and recognition of more subtle presentations of ASC. The recent DSM-5 (APA, 2013) descriptors of varying severity levels may serve to support this.

In addition, Cathy's story, in which Jake was diagnosed at the age of 16, highlights the issue of CYPs' consent, even when parents request support. This emphasises the importance of supporting parents of older CYP, who may feel powerless as the young person's rights increase, to be able to access appropriate support for themselves, regardless of whether a diagnosis is sought for the CYP. In Cathy's case, she considered that the diagnosis was highly beneficial to Jake, which highlights scope for developing age/stage appropriate information and advice for CYP in this age group. This would promote *informed* consent and reduce risks of uninformed refusal to assessment and potentially beneficial diagnoses.

#### *5.5.2 Implications for research*



I suggest that additional research should explore the earliest age of *possible* reliable diagnosis, not just in cases of at-risk toddlers (a limitation of previous research: Guthrie et al, 2013; Luyster, 2006), but also retrospectively in those who have received a later diagnosis. Whilst hindsight may influence parents and CYP to re-interpret previously unrecognised 'signs of ASC' through the lens of ASC, this could provide valuable insights, especially if data were triangulated with the views of professionals. Furthermore, this type of retrospective design would enable exploration of parents' or CYP's views about the most beneficial time to have been diagnosed in hindsight: is it really 'the earlier the better' in all cases? This could also facilitate a developmental lifespan approach to exploring parents' and CYP's views about the purposes and benefits (and any potential disadvantages) of diagnosis at different ages and stages of their development and within family lifespan development.

Research could also explore how the diagnostic experience could be improved for parents, including exploration of the reasons for delays in diagnosis: are they necessary and unavoidable, (such as gathering assessment information over time), or preventable, (such as improving multi-agency information-sharing)? Services for parents could also be improved by undertaking a needs analysis, or developing a needs profiling tool to assess individual parental needs. However, I remain sceptical about the possibilities for developing and providing appropriate interventions or support, given the unstable evidence about early intervention for CYP (Chapter 1), which remains a clear priority for research.

The exploratory and interpretative design of the current study resulted in detailed parental narratives about their experiences, but the significance of the *later* timing of the diagnosis was not always explicit. Future research could explore this more specifically, perhaps through the use of specific follow-up questions.

## CHAPTER SIX: DISCUSSION AND CONCLUSION

### 6.1 Overview

In this concluding chapter, I firstly discuss the contribution of the current study to existing literature and theory development, relating both to the substantive topic (later diagnosis of ASC) and to narrative methodology. I summarise the practical and research implications, including recommendations for future research. Finally, I critique the value of the current study's claims to knowledge (trustworthiness and dependability), whilst acknowledging its limitations.

### 6.2 Contribution of the Current Study

#### *6.2.1 Contribution to theory development: Substantive topic of later diagnosis of ASC*

Chapters One and Two argued the broad rationale for the current study, and raised some fundamental conceptual questions about the ontological status of ASC. I became curious about whether 'early' diagnosis (often conceptualised as 12-36 months; Chapter 1) is unequivocally *possible* and/or *necessary* in all cases, and whether the prevailing maxim, 'the earlier the better' is indeed universally *beneficial* for CYP and their families. The findings of the current study cannot, and do not, claim to answer these questions; rather, they offer a substantial foundation for beginning to address them. The current study explored two parents' narratives relating to their perceived *reasons* for later diagnosis of ASC, and gained insights into parental perspectives about the *impact* of receiving a later diagnosis.

Findings from RQ1 suggest that the reasons for later diagnosis of ASC are complex and highly individual, and cannot be ascribed to any singular or discrete variables, despite the efforts of previous research

to identify such ‘risk factors’. In each parental narrative of the current study, the later timing of the diagnosis was considered to arise from a complex and unique set of interacting factors (summarised in Table 12).

I position this finding as evidence to reject the essentialist view of autism as a discrete and stable entity, so often adopted (often implicitly) in existing research (Chapters 1 and 2). I propose instead, that an interactionist perspective is more appropriate in considering differential presentation across the lifespan (Frith, 2003; Karim et al, 2012; Yates and Le Couteur, 2013) and the influence of psycho-social factors (Verhoeff, 2013; Nadesan, 2005; Russell, 2010; Vacanti-Shova, 2012; Cicchetti and Toth, 2009) on CYPs’ level of functioning/impairment and concomitant parental concerns. The conceptualisation of ‘severity levels’ of ASC and contingent support required, alongside consideration of impairments to functioning has recently been adopted by DSM-5 (APA, 2013; Table 1), and I suggest that this interactionist conceptualisation of ASC and its severity need to become mainstream in theory, research and practice.

Findings from RQ2 suggest that the impact of the later timing of diagnoses (Kyle - 12 years; Jake – 16 years) on parents is also highly varied, with individual differences in parents’ perceptions of the most beneficial time (or age) for the diagnosis to have been made, in hindsight. This finding challenges the assumption of most existing literature that early diagnosis is universally beneficial. Findings of the current study suggest that striving for ‘early diagnosis’, which typically refers to diagnosing CYP as *young* as possible, should be reframed as assessing CYP as *soon* as possible, contingent on their arising needs (consistent with an interactionist perspective) and parental concerns.

Findings from the current study highlighted several important practical implications and recommendations for research, which are summarised in Tables 30-31.

Table 30: Summary of recommendations arising from RQ1: How do parents' narratives illuminate an understanding of the reasons for later diagnoses of ASC?

Recommendations for Practice	Recommendations for Research
<ul style="list-style-type: none"> <li>• Good practice guidance (e.g. NICE, 2011) for the assessment and diagnosis of ASC should be extended to other behavioural/developmental conditions, in order that: <ul style="list-style-type: none"> <li>○ Differential diagnoses and alternative hypotheses are explored and eliminated</li> <li>○ Information is gathered about the CYP in multiple contexts</li> <li>○ Multi-agency clinical judgement is drawn upon</li> <li>○ Comprehensive assessment takes place, including a full developmental history</li> <li>○ Parental concerns are taken seriously</li> </ul> </li> <li>• All medical and educational professionals should adopt a comprehensive hypothesis-testing approach, and share information between agencies.</li> <li>• Lead practitioners should consider the possibilities for a combined multi-agency pathway for diagnosing (formulating) various behavioural/developmental conditions (see research recommendations).</li> <li>• Suspected ASC should be discussed face-to-face with parents and relevant information should be provided to (and requested from) parents, with sensitivity to possible distress and/or confirmation bias.</li> </ul>	<ul style="list-style-type: none"> <li>• Arising from the literature review, more research is needed to establish the best possible interventions for ASC and support packages for families, particularly in relation to AOD.</li> <li>• Research should explore the possibilities for a combined multi-agency diagnostic pathway. This should include: <ul style="list-style-type: none"> <li>○ A comprehensive literature review to identify similar conditions, differential diagnoses and appropriate professional agencies in their assessment</li> <li>○ An action research project to pilot the pathway, whilst seeking feedback and evaluation to continually improve the process.</li> </ul> </li> <li>• Narrative research is valuable and should be used more to understand experiences and complex situations. For example, further research could explore: <ul style="list-style-type: none"> <li>○ Parents' narratives of differential diagnoses in childhood</li> <li>○ Professionals' narratives about exploring hypotheses and making clinical judgements about diagnoses and/or formulations.</li> </ul> </li> </ul>

*Table 31: Summary of recommendations arising from RQ2: How do parents evaluate the impact of the (later) timing of an ASC diagnosis?*

Recommendations for Practice	Recommendations for Research
<ul style="list-style-type: none"> <li>• Parental support should not be contingent on receiving a formal diagnosis: support should be timely and contingent on parents' contemporaneous concerns and needs.</li> <li>• Support packages should be sensitively designed to consider the impact of receiving a later diagnosis on parents' well-being and their own identity.</li> <li>• For CYP older than 16 years, their consent (or lack thereof) should not form a barrier to access to support and services for parents.</li> <li>• Professionals should always follow good practice guidance (e.g. NICE, 2011) never to dismiss parental concerns (NB offering reassurance is different from dismissing concerns; Ryan and Salisbury, 2012).</li> <li>• CYP's services should develop appropriate information and advice for CYP aged 16 years and older, for whom ASC is a consideration, in order to support them to give (or withhold) informed consent.</li> </ul>	<ul style="list-style-type: none"> <li>• Research should seek to develop a parental needs analysis tool, such that parents needs can be identified and addressed.</li> <li>• Further research could focus in more detail on the impact of the later timing of the diagnosis, by asking parents specific follow-up questions in relation to this, including questions about the impact on their own well-being and identity.</li> <li>• Research could seek to identify the earliest possible AOD in individual cases of later diagnosis, in hindsight.</li> <li>• Retrospective research (with those who have received a later diagnosis) could also inform understanding of parents' and CYPs' perceptions of the most beneficial time to have received the diagnosis.</li> </ul>

### *6.2.2 Contribution to theory development: Narrative methodology*

I conclude that the application of narrative methodology to explore the perspective of parents of CYP who are diagnosed 'later' with ASC (after 12 years) has afforded valuable new insights. By looking holistically and chronologically at individual stories (and the inter-linked events within them), the narrative approach offered the unique benefit of constructing explanatory narratives. Preserving the richness and complexity of each individual story allowed participants and me jointly to interpret the significance of each event in relation to the 'plot': receiving a later diagnosis of ASC. The narrative approach facilitated simultaneous exploration of descriptive experience narratives, in order to understand the impact of the later diagnosis on parents.

The current study also contributes to the narrative methodological literature: namely demonstrating the possibilities for eliciting rich data and deep analyses. This should be celebrated, though I urge fellow narrative researchers and those considering using the approach, to exercise caution; in particular, not to be tempted by positivist values of generalisability leading to gathering data from more than one or two participants. This would likely sacrifice the richness of data and depth of analysis.

### *6.2.3 Summary*

From the findings of the current study, I conclude that seeking very early diagnoses (i.e. at the youngest ages of 12-36 months) is not always beneficial, nor indeed possible or necessary. This seemingly controversial finding challenges the dominant essentialist view of autism, and suggests that an interactionist view is more appropriate to understand the complex reasons for later diagnoses of ASC.

The current study provides a strong rationale for future research to strengthen (or challenge) my initial exploratory findings. My final aim is to invite other researchers to build upon the findings of the current study (recommendations in Tables 30-31) and collaboratively contribute to developing a shared understanding of when ASC *can* and *should* be diagnosed, with the ultimate aim of promoting the best outcomes and experiences for CYP and their parents.

### **6.3 Trustworthiness (Validity), Dependability (Reliability) and Plausibility**

In Section 3.10, I argue, from my social constructionist epistemological perspective, for the reframing of ‘validity’ as the ‘trustworthiness’ of data and their analysis, and ‘reliability’ as the ‘dependability’ of the data (Webster and Mertova, 2007), in order to evaluate the overall credibility of the current research (Polkinghorne, 1995). Mishler (1990) conceptualises validation as a *process* in which the researcher evaluates his/her own research’s ‘trustworthiness’, which I now undertake.

Reissman (2008) suggests that trustworthiness (validity) should be considered at two levels: (i) the trustworthiness of participants’ narratives; and (ii) the trustworthiness of the analysis, interpretations and conclusions. Firstly, I consider that the trustworthiness of participants’ narratives is indeed enhanced by the flexible design of the current study’s interview (Section 3.6), which allows participants to select relevant events and experiences, and offer *their* interpretation of these. As Elliott (2005, p. 26) suggests, this is advantageous, as the aim is not to provide “an unproblematic window on what happened”; rather, the focus is on participants’ interpretation and sense-making of their events and experiences. Throughout the current study, I have acknowledged that narratives are time- and context-dependent (Clandinin and Connelly, 2000) and have made explicit the contextual factors that are likely to have shaped the generation and co-construction of the narratives (Section 3.8.2). I acknowledge that participants of the current study might tell a modified narrative at a different time or in a different context. Some researchers consider this a

threat to the 'replicability' or 'dependability' of the research. I argue, however, that context-dependent knowledge still has value (Bathmaker, 2010) and does not invalidate findings. My transparency and reflexivity in reporting the current study has sought to address this, in order that readers can make their own judgements about contextual influences.

Secondly, Reissman (2008) advocates evaluating the trustworthiness of the analysis, interpretations and conclusions. The interpretive approach of the current study is vulnerable to criticism by positivist and realist researchers seeking 'the essential truth' and authoritative meaning (Bruner, 1990). The social constructionist and relativist assumption of the current study deems there to be several possible meanings and interpretations, with no one single 'truth'. Bruner (1990, p. 27) suggests that critics over-emphasise "the dreaded form of relativism where every belief is as good as every other" (p. 27). I argue, alongside Emmerson and Frosh (2009), that the plurality of possible interpretations does not invalidate my interpretations and conclusions; rather, it highlights the importance of taking steps to address this issue. To strengthen my claim to trustworthiness, I have exercised transparency through my use of careful documentation of data generation and analysis procedures (Reissman, 2008). These are described in detail in the main report (Sections 3.4-3.9), with meticulous use of supplementary appendices. My extensive use of direct quotes from participants (Chapters 4 and 5) is also intended to enhance the persuasiveness of my interpretation of the findings (Reissman, 2008). Providing reflexive discussion (Section 3.6.4) is also considered to address the 'crisis of representation' (plurality of meanings; Elliott, 2005), because the researcher explicitly reflects upon the influences on their particular interpretations. This allows readers to make their own judgements about the plausibility of knowledge claims.

Furthermore, as argued by Yardley (2000; Section 3.10; Table 11), I consider that the value of research is not limited to its trustworthiness and dependability. In particular, research can be evaluated based on its 'impact and importance' (Yardley, 2000). I have provide a clear rationale for the importance of the current study, based on identified gaps in existing literature (Chapters 1 and



2). Reissman (2008) argues that the ultimate test of validity is in the pragmatic use of research: does the research form a basis for further research? As described in Section 6.2, an aim of the current research is to inspire further research, in order collectively to build knowledge and understanding of later diagnosis of ASC. I also demonstrate 'sensitivity to context' (Yardley, 2000), by reflecting on the contribution of the current study in relation to existing literature (Chapters 4 and 5). In Section 6.2 I demonstrate sensitivity to the wider context of the research and the overarching conceptual questions which frame it. My conclusions and written style throughout are appropriately tentative: I have avoided making law-like claims (Elliott, 2005) that run deeper than the findings of the current study.

#### **6.4 Limitations**

I acknowledge one potential limitation in the interpretative design of the current study: it was problematic to infer the precise impact of the *later timing* of the diagnosis for parents. Although Maria and Cathy's naturally occurring 'comparators' (what might have been different if their sons were diagnosed earlier) provided some useful insights into the impact of AOD, I did not directly ask how they perceived the AOD had affected their experiences. Neither did I generate narratives with other parents who had received an earlier diagnosis to establish a comparison group. A future comparative study could seek to address this, as could a design similar to the current study, with additional follow-up interviews.

An obvious potential criticism of the current study is the very small sample (n=2) and its potential lack of representativeness: readers with positivist assumptions may be tempted to discount the findings based on their likely poor 'generalisability'. Whilst some narrative researchers consider that at least *some* degree of generalisability is necessary (Elliott, 2005), others argue that

generalisability is not even desirable (Reissman, 2008). I adopt the latter view: generalisability is not an aim of the current study.

In defence of case study research, Flyvbjerg (2006) makes some useful arguments against the perceived need for generalisability that are also relevant to the current study. He argues that formal generalisation is just one way of developing knowledge and is overrated. Studies that lack (or do not aspire to) generalisability can still be included in “the collective process of knowledge accumulation” (Flyvbjerg, 2006, p. 10) and can help “cut a path toward scientific innovation”. Flyvbjerg (2006, p. 12) concludes that “the force of the example is underrated”. The current study, although not a case study design, embraces this principle: participants were selected as examples or ‘informants’ (Shedki, 2005) on the phenomenon of later diagnosis of ASC. As the current research sought to explore individual stories in detail over time, such a small sample was considered appropriate. Moreover, with no desire to generalise, I did not seek a ‘representative’ sample: merely those who met the selection criteria (Table 9).

Arising from this perspective, however, I acknowledge a limitation to the current study’s conclusions: I am unable to draw law-like claims about the reasons for, and impact of, later diagnosis of ASC. I consider that these ambitious conceptual research questions could not be adequately addressed by a single research study, regardless of its sample size and claims to generalisability. Instead, I propose that the current study offers useful insights from Maria and Cathy’s narratives (as ‘examples’ of parents whose CYP has experienced a later diagnosis of ASC) and it paves the way for future studies collectively to continue to address the wider questions.

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## **APPENDICES TO VOLUME 1**

*LATE(R) DIAGNOSIS OF ASC: USING PARENT NARRATIVES TO UNDERSTAND THE CONTEXTUAL FACTORS ASSOCIATED WITH LATER DIAGNOSIS AND ITS IMPACT ON CHILDREN AND FAMILIES*

By

Fiona Eloïse Cane

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## **Appendix 1: DSM-5 criteria autism spectrum disorder (APA, 2013)**

### **AUTISM SPECTRUM DISORDER**

This appendix gives an outline of the most recent diagnostic criteria for Autism Spectrum Disorder, as described in DSM-5 (APA, 2013). The manual itself provides the full descriptors, examples and criteria: the overview below cannot be used to make diagnoses.

- “Persistent deficits in social communication and social interaction across multiple contexts”,  
with reference to deficits in:
  - Socio-emotional reciprocity
  - Non-verbal communication and social interaction
  - Developing, maintaining and understanding relationships
  
- “Restricted, repetitive patterns of behavior, interests, or activities” with regards to:
  - Stereotyped or repetitive movements, speech or use of objects
  - Inflexibility, routines, rituals, rigid thinking etc
  - Interests are restricted, fixed or intense
  - Unusual sensory processing pattern

## Appendix 2: A Brief History of Autism

Table A1: A brief history of autism

Author/Date	Noteworthy Developments in the Conceptualisation of Autism	Reference(s)
Bleuler (1911)	The word 'autismus' was first used to describe some of the symptoms of schizophrenia by Swiss psychiatrist, Bleuler. This description is derived from the Greek 'autos' meaning 'self' and refers to altered social affect.	Gallo (2010) Chambers (1969)
Kanner (1943)	In one of the most widely cited papers in the history of autism, Leo Kanner described 11 cases from which he introduced the idea of autism as a distinct syndrome, characterised by: <ul style="list-style-type: none"> <li>• Profound autistic withdrawal</li> <li>• Obsessive desire for sameness</li> <li>• Good rote memory</li> <li>• An intelligent and pensive expression</li> <li>• Mutism or language without communicative intent</li> <li>• Over-sensitivity to stimuli</li> <li>• A skilful relationship to objects</li> </ul>	Kanner (1943) Chambers (1969) Jordan (1999)
Kanner (1944)	Used the term 'early infantile autism'.	Chambers (1969)
Asperger (1944)	In parallel, but in isolation from Kanner's work, Hans Asperger simultaneously developed some very similar ideas, although his work received less attention at the time because he published in German. His cases tended to have similar difficulties with relating to the world, but were higher functioning. He termed this 'autistic psychopathy', which later became known as Asperger(s) Syndrome (see DSM-IV, 1994 and DSM-IV-R, 2000). Asperger placed more emphasis on the strengths, capacities and gifts of these children.	Jordan (1999) Roth (2010) Feinstein (2010)
DSM-I (1952) and DSM-II (1968)	Neither version included a definition of 'autism'. At this time, 'childhood psychosis' and 'childhood schizophrenia' were used as synonyms for autism.	Roth (2010) Jordan (1999)
Rutter (1978)	Conceptualised autism as a categorically distinct disorder, distinguishing it from other psychiatric conditions (e.g. schizophrenia) and other developmental conditions (e.g. language impairments).	Baron-Cohen (2008)
Wing and Gould (1979)	Wing and Gould (1979) conducted a landmark study, in which they describe the presence of more diverse behavioural presentations and conclude that autism can occur in children of all range of cognitive abilities. Although not directly mentioned in the paper, ideas about the autism 'spectrum'	Wing and Gould (1979) Jordan (1999) Wing (1996)

	and the 'triad of impairments' are thought to originate from this study.	
DSM-III (1980)	<p>Autism was introduced under the broad category 'Pervasive Developmental Disorders' (PDD). Criteria for 'infantile autism' were:</p> <ul style="list-style-type: none"> <li>• lack of responsiveness to others</li> <li>• language absent or abnormal</li> <li>• resistance to change or attachment to objects</li> <li>• absence of schizophrenic features</li> <li>• onset before 30 months</li> </ul>	Roth (2010)
Wing (1992)	Moving away from the idea of autism as a discrete categorical disorder, Wing introduced the idea of a 'spectrum' in 1992.	Wing (1995)
Wing (1995, 1996)	<p>Describes the 'triad of impairments' affecting:</p> <ul style="list-style-type: none"> <li>• social interaction (including affective contact)</li> <li>• social communication (including speech and language development)</li> <li>• imagination (including pretend play and conceptualising abstract concepts such as past, present and future)</li> </ul> <p>Wing (1995) also notes that these impairments are always accompanied by limited, narrow and repetitive activities.</p>	Wing (1995, 1996)
DSM-IV (1994) and DSM-IV-R (2000)	Pervasive Developmental Disorders are described as having distinct subtypes, including autistic disorder, Asperger's disorder and 'pervasive developmental disorder not otherwise specified' (PDD-NOS, sometimes known as 'atypical autism').	Roth (2010)
DSM-5	<p>Diagnostic criteria have now reduced from three classes of symptoms (triad of impairments) to two:</p> <ul style="list-style-type: none"> <li>• social communication and interaction difficulties</li> <li>• repetitive or restrictive behaviours</li> </ul> <p>The DSM-5 now specifies that symptoms must cause "clinically significant impairment in social, occupational, or other important areas of current functioning" (APA, 2013, p. 50). It offers guidance on the severity of impairment on three levels: (i) requiring support; (ii) requiring substantial support; and (iii) requiring very substantial support.</p> <p>The DSM-5 has also introduced a new category, 'Social Communication Disorder', but the evidence for this as a discrete diagnosis is limited (Singer, 2012) and the validity is questionable (Ozonoff, 2012). It is considered to possibly represent a category that may have previously have been known as 'PDD-NOS' or 'atypical autism'.</p>	<p>APA (2013)</p> <p>Singer (2012)</p> <p>Ozonoff (2012)</p>

## Appendix 3: Full interview guide

### Interview Guide

#### Part 1: Introductions and rapport building

- Participants will be thanked for agreeing to meet with me.
- I will engage in neutral, rapport-building conversation topics (such as asking participants how their day has been so far)
- The participant information sheet will be discussed and the expectations of participation will be clarified.
- If parents do still agree to participate, their signature will be sought on the informed consent form.

#### Part 2: Outlining the life chapters (McAdams, 1993)

- Participants will be presented with a large, empty 'timeline' (a long, landscape piece of paper), representing the life of their child.
- I will explain that this is intended to give a framework for discussion, and to plot events in chronological order, although they may be discussed in any order.
- Firstly, participants will be asked to imagine their child's entire life as a book (or a film), and asked to divide it up into a series of 'chapters'. They will be informed that they can have as many chapters as they like, ideally ranging from 2-8. They will be given cards (see below) to write the title of the chapters and the age range (of the child) that the chapter includes (this can be any length of time).
- Participants will be given plenty of time to think about this and plot the chapters onto the timeline.

#### Part 3: Identifying critical events

- Participants will then be asked to tell me, in as much detail as possible, about an important memory from each of the life chapters.
- I will then use appropriate follow-up questions and probes (see examples below) to elicit more detail and further information about these events.
- Participants will then be asked, using prompt cards (see below), to identify along the timeline:
  - A peak experience (best moment)
  - A nadir experience (worst moment)
  - A key turning point.

#### Part 4: Significant people

- Participants will be asked to think of 2 or 3 significant people or 'characters' who have had a significant impact in the child's life, and to discuss these in detail.

#### Part 5: Future scripts

- Participants will be asked to add one or more 'chapters' for the future and asked to describe, in detail, how they predict the future will be for their young person,
- In consideration that participants may not have considered their child's future, completion of these cards will be optional, inviting participants to use any combination of the short, medium and/or long term prompt cards (see below).



#### Part 6: Themes (reflections on the whole experience)

- Participants will be asked the following questions:
  - Looking back, how would you summarise this whole experience?
  - Thinking about all the key events and characters, can you identify a particular theme that runs through the story?
  - Thinking back to the idea of your young person's life as a book/film, can you think of a title for it?

#### Part 7: Debriefing

- Participants will be given the opportunity to tell me anything else that they feel is relevant.
- They will then be thanked for taking part, and asked the following questions:
  - How was this interview experience for you?
  - How have you been left feeling now?

#### **General Probe Questions (examples):**

The following are examples of follow up questions/probes to elicit more detail or further information:

##### More information

- Tell me more about that.
- What else?
- Go on...
- What happened next?

##### Clarify meaning

- What do you mean by that?
- Can you explain what you mean?
- Have I got this right?
- In what way...?

##### Eliciting an evaluation

- How would you describe that time? For yourself? For your son/daughter? For your family?
- How did that make you/them feel? How did you/they feel at that time?
- What was that like for you/them?
- What was the outcome/result of that?
- How did that end?

##### Getting examples

- Can you give an example?
- Tell me about a time when that happened...

## Interview Resources

1. Long strip of paper (to form timeline)

2. Life Chapter Prompt Cards:

<p style="text-align: center;"><b>Chapter 1</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 2</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 3</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>
<p style="text-align: center;"><b>Chapter 4</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 5</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 6</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>
<p style="text-align: center;"><b>Chapter 7</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 8</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>	<p style="text-align: center;"><b>Chapter 9</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Age range: .....)</p>

3. Key Events Cards:

<p style="text-align: center;"><b>A peak experience</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Approx. age: .....)</p>	<p style="text-align: center;"><b>A nadir experience</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Approx. age: .....)</p>	<p style="text-align: center;"><b>A key turning point</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>(Approx. age: .....)</p>
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#### 4. Significant people

Person 1	Person 2	Person 3
<i>Name/role:</i>	<i>Name/role:</i>	<i>Name/role:</i>
.....	.....	.....
.....	.....	.....
.....	.....	.....

#### 5. Future chapter cards:

Short-term future	Medium-term future	Long-term future
.....	.....	.....
.....	.....	.....
.....	.....	.....
<i>(Approx. age: .....)</i>	<i>(Approx. age: .....)</i>	<i>(Approx. age: .....)</i>

## Appendix 4: Participant information sheet

### Participant Information

Please read the following information. If you would like to participate in this research, please sign the consent form.

#### **What is this research for?**

- The aims of the research are:
  - To understand of parents' views about the key events preceding their young person's later diagnosis of ASC (defined as aged 12 years or older).
  - To understand the perceived impact of the diagnosis on young people and their families.

#### **What will participation involve?**

- The interview will last between one and two hours.
- The process will involve an in-depth discussion about your son/daughter's entire life history, asking you to recall and reflect upon key events throughout their life and describe them in detail.
- The interview will be audio-recorded for the researcher to listen back to, as not everything can be written down at the time.

#### **What will happen to my data?**

1. **The audio-recording** – this will be transferred to a password-protected USB memory stick and/or saved on a password-protected Local Authority computer, which will be stored on the researcher's own work drive. Only the researcher and IT/admin staff will have access to this. The interview will then be permanently deleted from the Dictaphone.
  2. **The transcript** - the exact words spoken during the interview will be typed into a transcript. No names (of individuals or organisations) will be used in transcripts: instead, pseudonyms will be used. Transcripts will be stored electronically as above. Any printed (hard) copies and hand-written notes will be stored in a locked filing cabinet at the Local Authority offices or in a locked cupboard at the researcher's home.
- All data will be stored, in line with the Data Protection Act (1998), at the Local Authority for a period of 10 years. After this time, all electronic data will be deleted and printed data will be shredded.

#### **Is my data confidential?**

- Yes! Anything that you say will be treated as confidential, which means that it cannot be identified as yours.
- Pseudonyms will be used throughout the transcript and research report. Family relationships or professional roles may be referred to (e.g. brother, teacher or doctor).
- Every care will be taken to minimise the reporting of specific or unique case details that may reveal your identity. Please inform the researcher if there is anything that you would like to be left out.
- If, for any reason, the researcher becomes seriously concerned about your own or others' safety and/or well-being, she has a responsibility to pass on this information to the university tutor or

placement supervisor, in order to decide how to offer support. This will be fully discussed with you first.

### **How will the research be reported?**

1. **Doctoral Thesis report** - This research study will be written into a 25 000 word doctoral thesis report for the University of Birmingham, which will be published, in full, online on the e-theses database. An edited, shorter version may be submitted to a peer-reviewed journal for publication, and findings from the study may also be disseminated at conference.
2. **Reporting to the ASC strategy group** – Findings (including an oral presentation and a four-page written summary) will be reported to this multi-professional stakeholder group, which comprises of a range of professionals interested in or working with children, young people and adults with ASC.
3. **Reporting to participants** – you will also receive a four-page written summary report, either by post or email (see below).

### **What if I change my mind?**

- You have a right to stop the interview (and the recording) any time, without having to give a reason.
- You also have the right to withdraw any part of your interview. You can choose to exclude specific comments from the interview transcript and this will not be analysed by the researcher. However, it will not be possible to erase this from the audio recording.
- If you choose to completely withdraw during or immediately after the interview, the recording will be deleted from the Dictaphone immediately.
- Following the interview, you can withdraw your data from the research, for a period of up to 7 days, by contacting the researcher (see contact details below).

### **Where can I seek further information and advice?**

[Information excluded for confidentiality]

### **Questions/concerns**

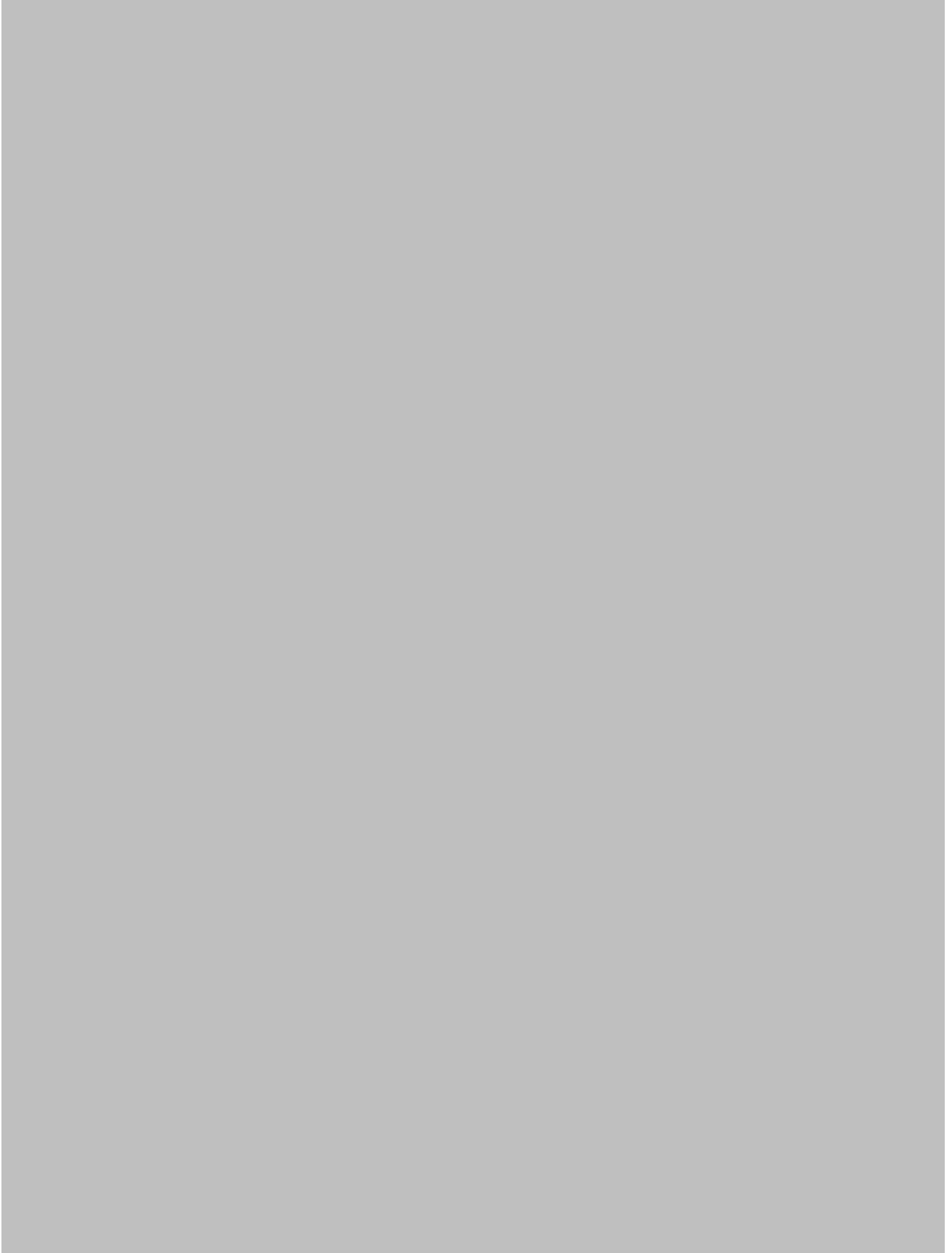
- Please feel free to ask the researcher any questions you may have now.
- There will also be opportunity for questions and discussion after the interview.
- If you have any remaining questions or concerns after the interview, please use the following contacts:

[Information excluded for confidentiality]

**Appendix 5: Application for ethical review**

<b>UNIVERSITY OF BIRMINGHAM</b> <b>APPLICATION FOR ETHICAL REVIEW</b>	<i>OFFICE USE ONLY:</i> Application No: Date Received:
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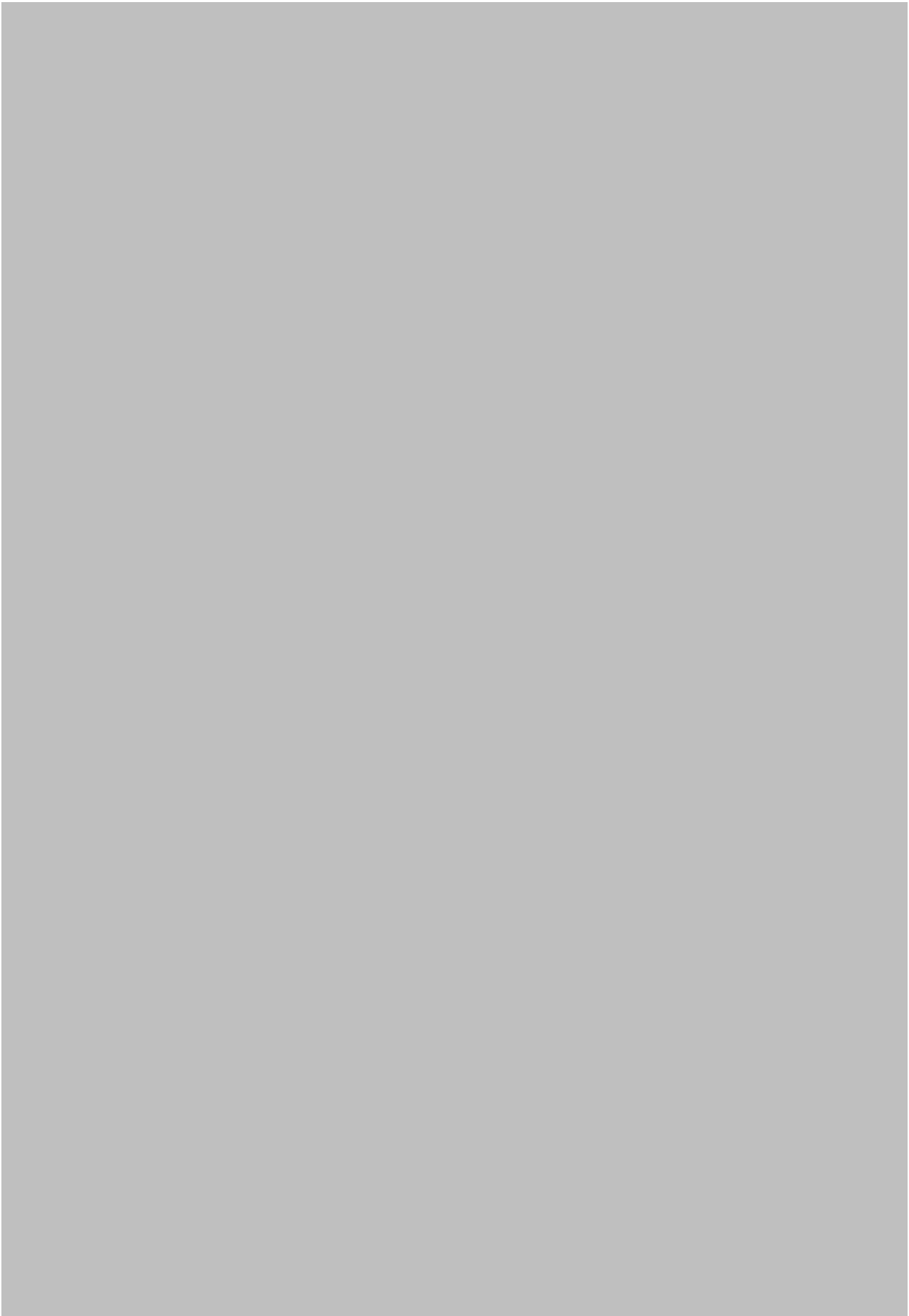


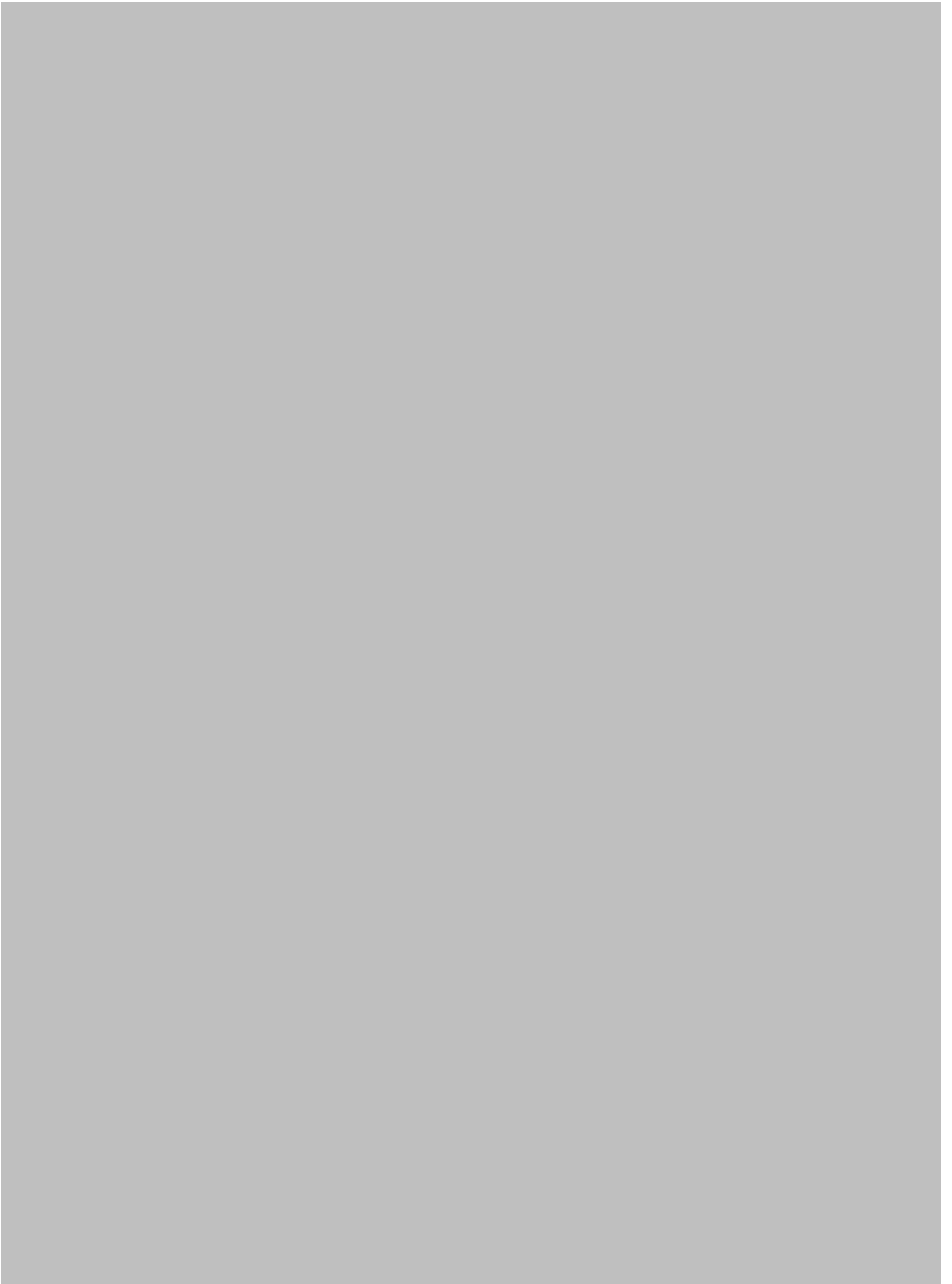






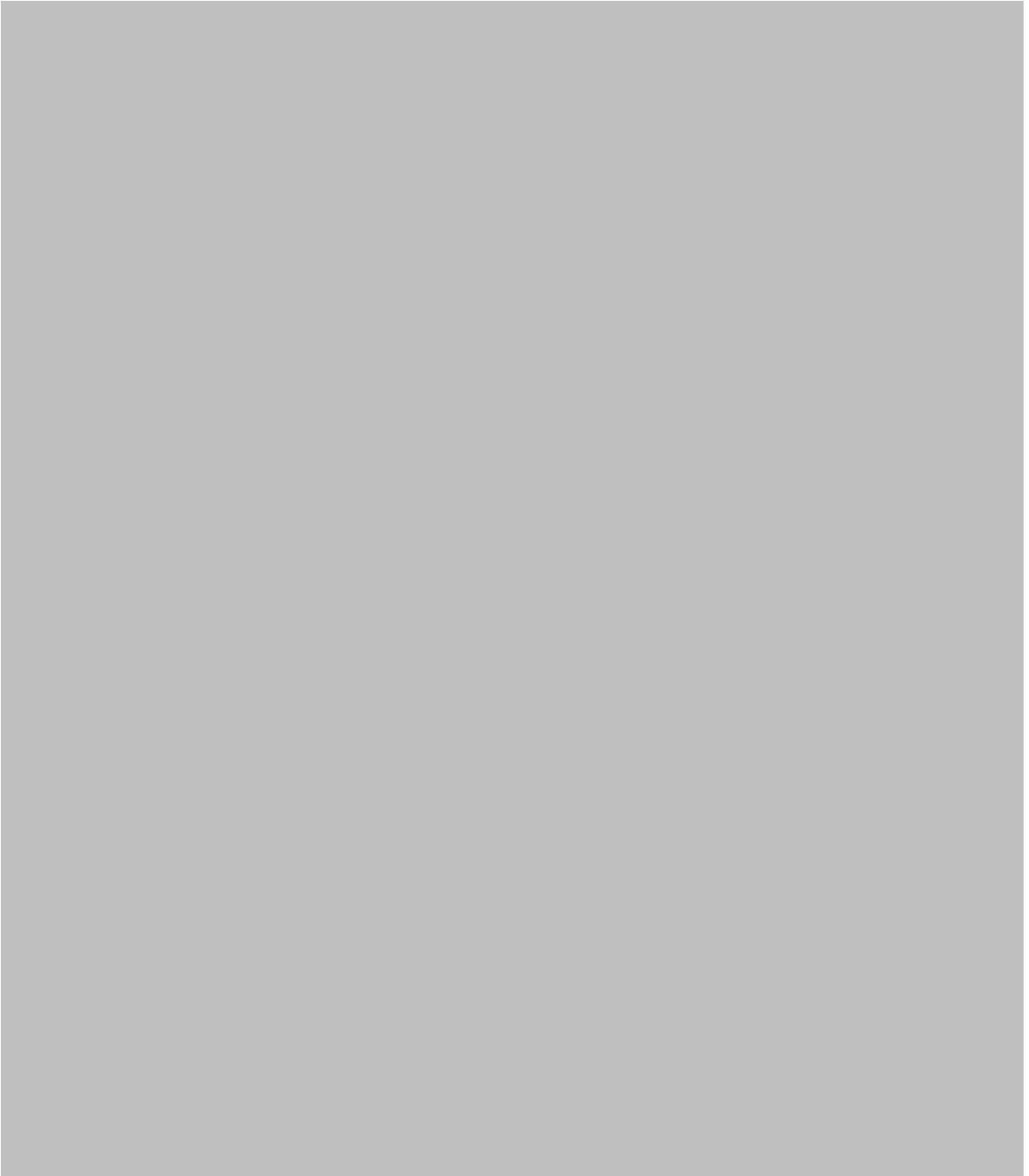


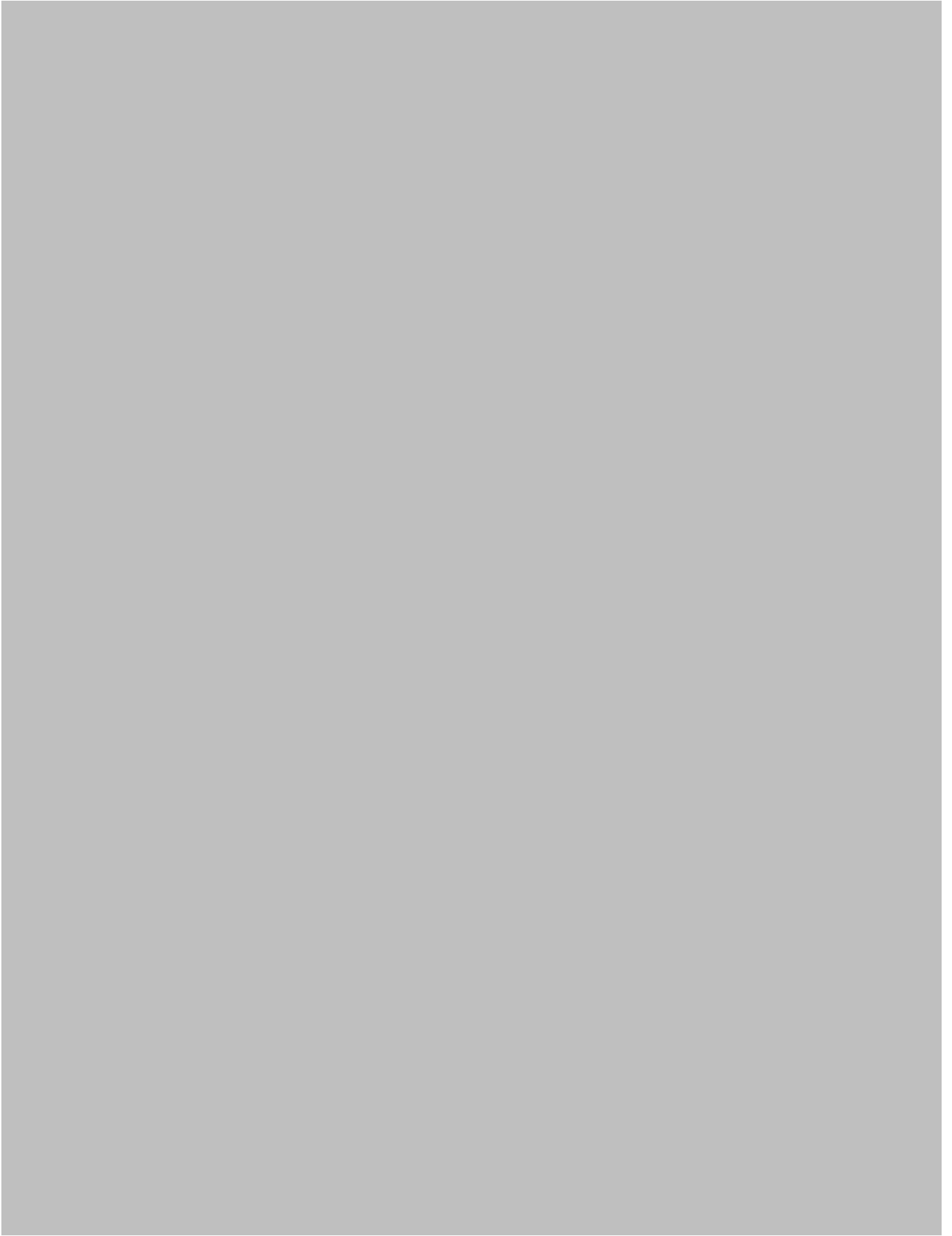










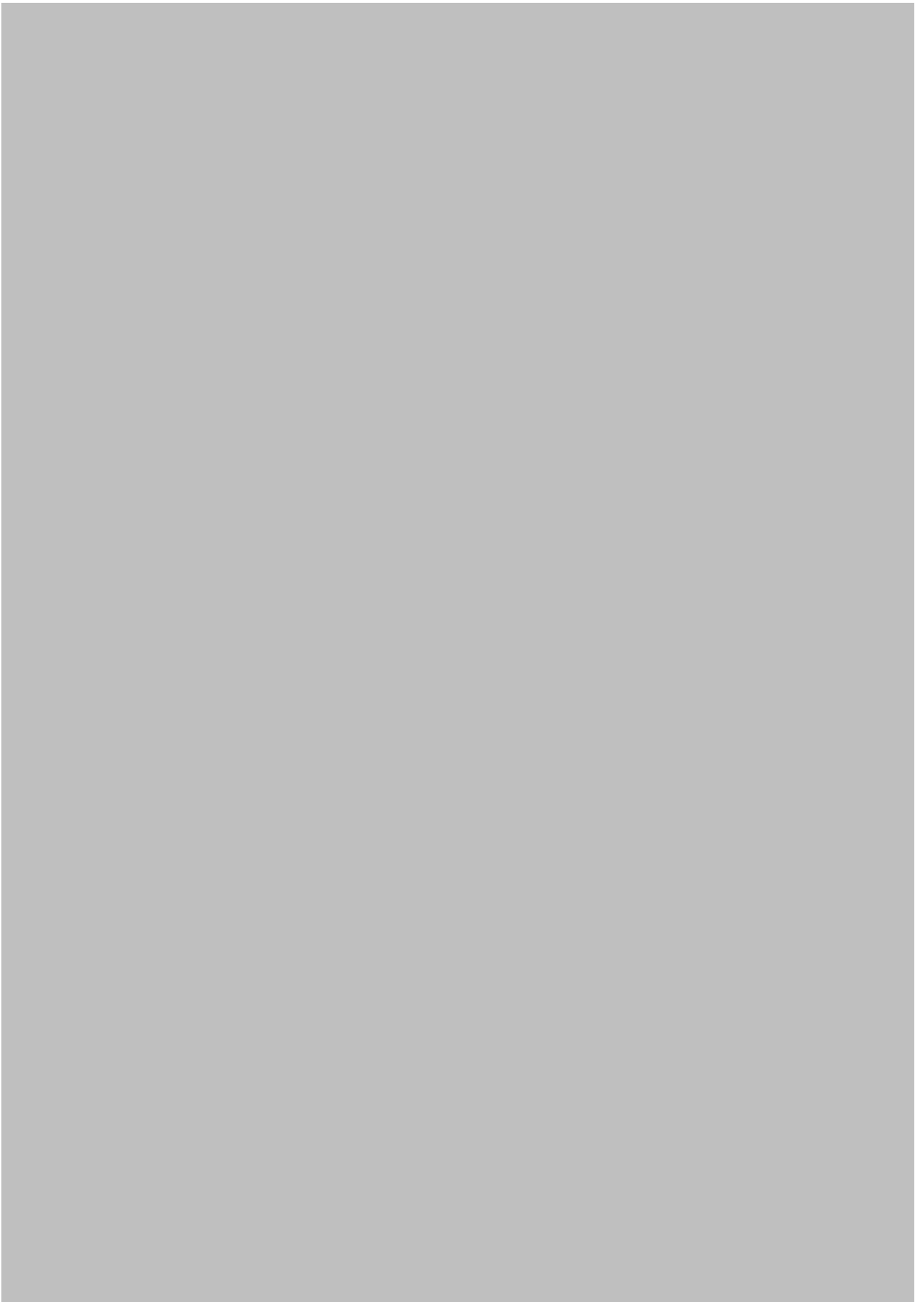


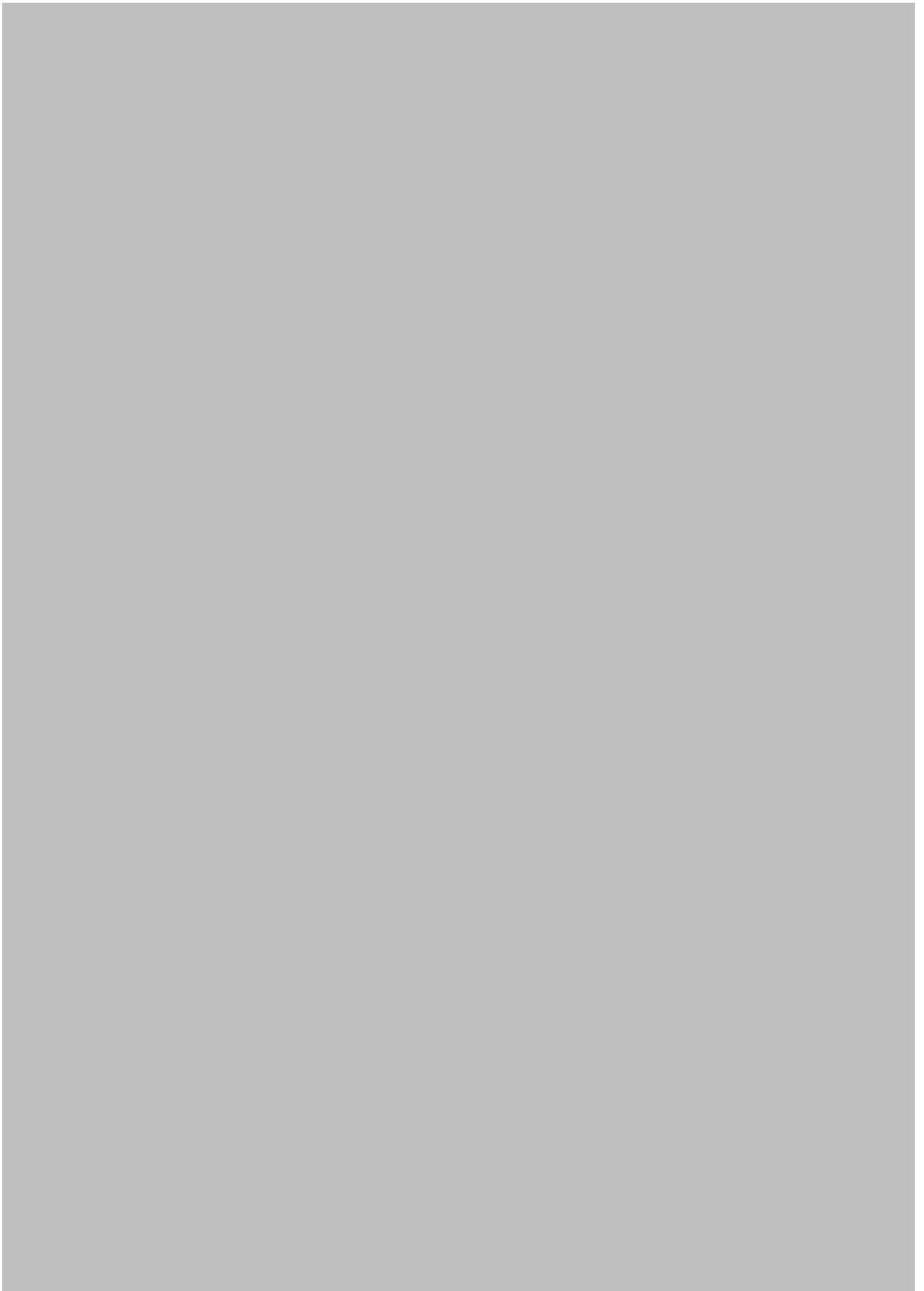


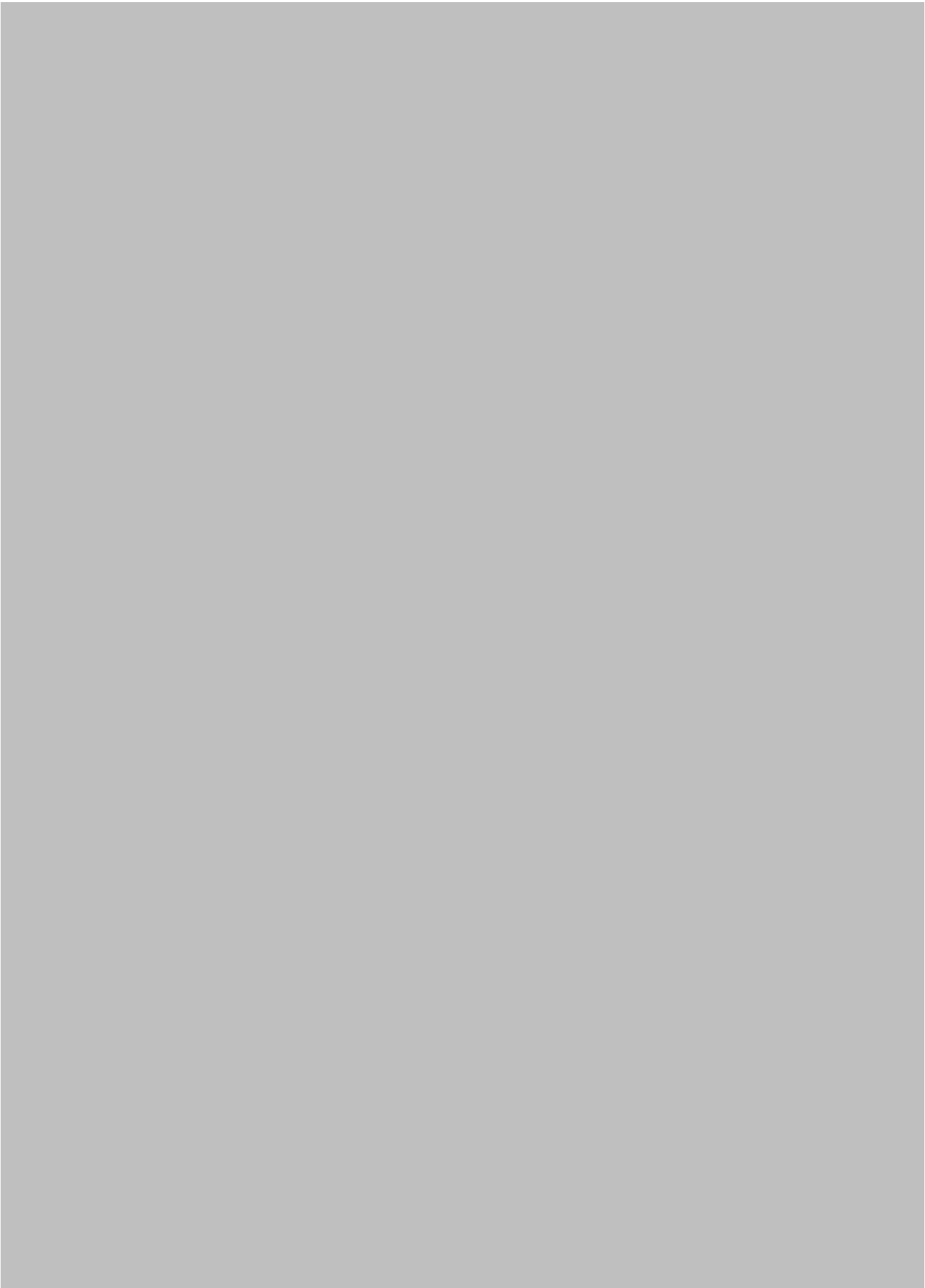














<INSERT DATE>

Dear <INSERT PARENT'S NAME(S)>,

**RE: Opportunity to participate in research: 'late diagnosis' of autism**

I am writing on behalf of Fiona Cane, a Trainee Educational Psychologist, at the University of Birmingham, to invite you to participate in a research study. The study will explore the views of parents of young people who have received a 'later' diagnosis of an Autism Spectrum Condition, including Asperger's Syndrome. You have been selected because <INSERT CHILD'S NAME> was referred to the ASC panel and diagnosed with an Autism Spectrum Condition after the age of 12 years.

For this study, Fiona is seeking parents willing to undertake an in-depth 1:1 interview, either at your home or at a Local Authority office near to your home (whichever would suit you best). You would discuss and reflect together upon the key events throughout <INSERT CHILD'S NAME>'s life, as well as discussing your perceptions of the impact of the diagnosis, and its timing, on <INSERT CHILD'S NAME> and your family.

If you are interested in participating, or have any questions about the study, please contact Fiona directly via telephone [omitted], email [omitted] or post. Please see the attached information sheet for her full contact details and further information about the study.

Participation in this research is entirely optional. If you do not wish to participate, simply ignore this letter and I will not contact you about this again. Please be reassured that your contact details will not be passed on.

Yours sincerely

<SIGNATURE TO BE ADDED>

[Name omitted]

Specialist Senior Educational Psychologist

Chair of Autism Spectrum Conditions Diagnostic Panel

## **Appendix 7: Additional details about data analysis**

Consistent with my claim to transparency, in this appendix I provide further details about my data analysis procedures in relation to each research question.

**Research Question One:** How do parents' narratives illuminate an understanding of the reasons for later diagnoses of ASC?

As illustrated in Figure 1 (Chapter 3), data analysis for RQ1 involves restorying participants' event-centred narratives, whilst preserving contextual and evaluative information about the significance of events in relation to the plot. Although analysing the main referential (event-centred) function of narrative is essential to develop an explanatory story, the evaluative (experience-centred) function of narrative is considered equally important (Labov, 1972): to understand the meaning and significance of events for the speaker (Cortazzi, 1993; Polkinghorne, 1988) and understand their perspective on what happened (Patterson, 2013).

From the main interview transcript, I defined the 'core narrative' (Mishler, 1986b) or 'mainline plot' (Gee, 1991) as the key events and happenings that either participants or I deemed relevant to the 'plot' (receiving a later diagnosis of ASC). The criticality and significance of events are defined by their impact on human understanding and action: "the level of criticality becomes evident as the story is told" (Webster and Mertova, 2007, p. 83). However, Polkinghorne (1995) highlights that a narrative configuration is not merely a direct representation of participants' thoughts and actions: interpretation and sense-making are essential to understanding their significance to the plot. The relevance and criticality of events and actions were, therefore, established at two levels: (i) participants' overt evaluation of the significance of events and; (ii) my subsequent interpretation.



In order to guide my initial analysis and interpretation, I therefore ruminated upon the data ('indwelling'), guided by the following questions:

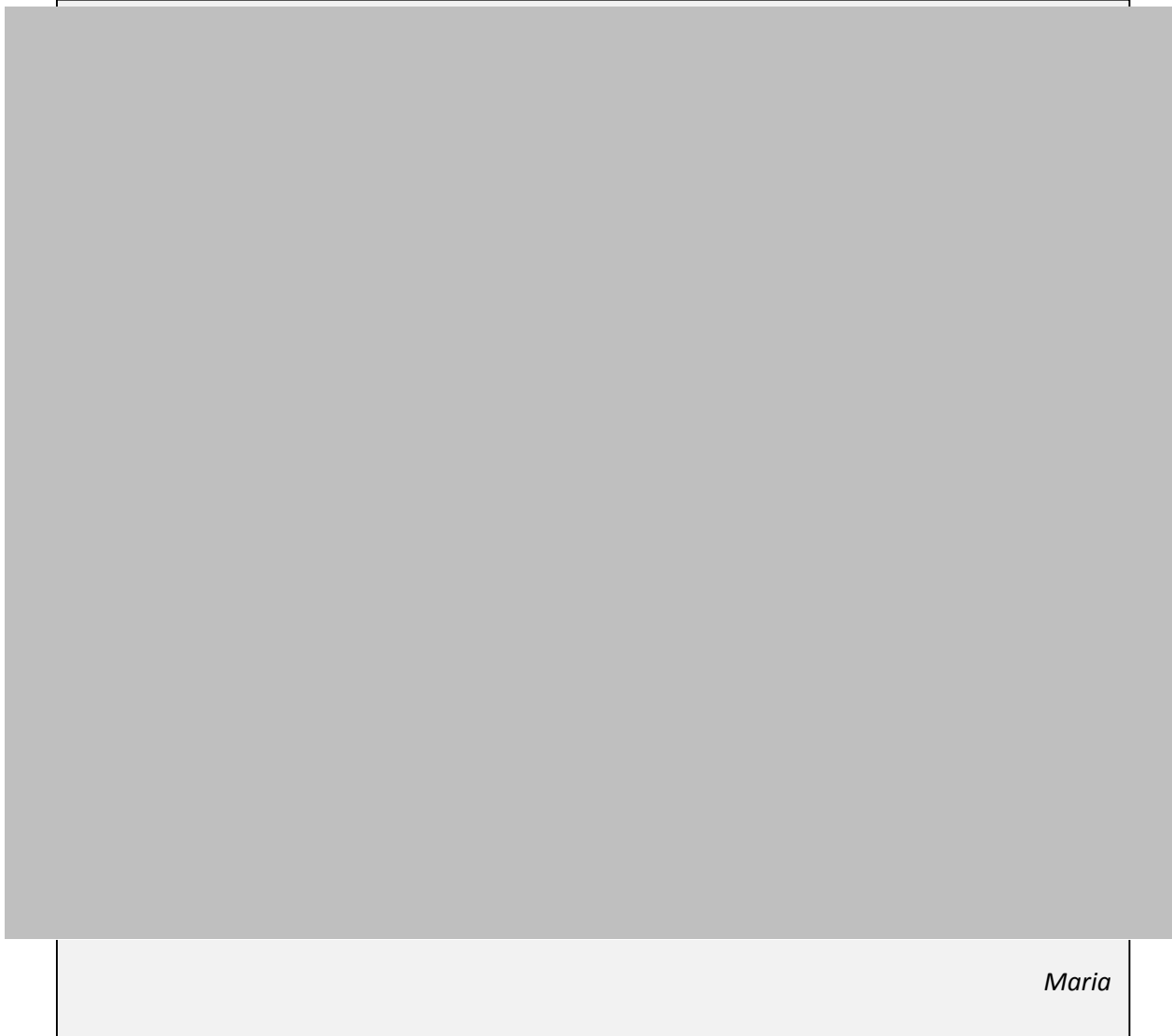
- Does the participant overtly consider this relevant to the mainline plot?
- Could this extract possibly explain the reasons for later diagnosis in this narrative?
- What would happen if this extract/event was removed from the story?
- Is this relevant to addressing Research Question One?

Subsequently, in seeking to condense and smooth the narrative configuration and to reduce its length to a digestible explanatory story, I was guided by the following questions:

- What is the most relevant/salient extract that captures the event or memory?
- Does omitting this segment/extract alter the understanding of the reasons for the timing of the diagnosis in this narrative?
- Has this segment been repeated? Has the participant already made this point?
- Is this just background/orientation information?
- Could this extract be truncated or condensed (marked with an ellipsis) whilst still capturing the key event?

As noted in Section 3.8.2.1, Maria told me that she had participated in previous research focusing on parents' experiences of raising a CYP with special needs and the effect on parents' own lives and identities. This, alongside my interpretation of her need/desire to reflect upon her own identity in a therapeutic context, perhaps influenced her tendency to 'drift' into segments of general reflections and descriptions, marked by her use of present tense to describe 'how it is', rather than past tense narratives about 'what happened' ( Box 1). Gee (1991) describes this material as 'off the main line plot', which often comprises generic events, repeated or habitual events and is are often told in the present or present perfect (simple or continuous) tense.

*Box 1: Extract from Maria's interview: an example of 'off the mainline plot' content (excluded from analysis)*



Whilst understanding parents' everyday experiences of raising a CYP with ASC is an important area of research, as noted in Section 2.4.1, it was not the focus of the current study. During the interview, my primary purpose was sensitive attunement to participants' needs. I sought, therefore, to strike a balance between Maria's apparent need to express her thoughts and feelings, and my agenda of generating data relevant to the research aims. I achieved this by gently guiding the interview, for example by waiting for a natural pause and saying "sorry to cut you off, but just to move us on..."

During my analysis and interpretation, I justify omitting these sections from analysis, on the basis that Mishler (1986b) posits that it is common practice to delete or ignore aspects of interviews that are not directly relevant to answering the research questions. Furthermore, Polkinghorne (1995) acknowledges that not all data elements are required to tell the story. Elements which do not contribute to the plot are omitted from the final narrative configuration: this is known as narrative smoothing (Polkinghorne, 1995).

**Research Question Two:** *How do parents evaluate the impact of the (later) timing of an ASC diagnosis?*

The tables below outline the external (Table A3) and internal (Table A4) evaluation devices described by Labov (1972) and expanded upon by Cortazzi (1993). I have given examples from the current study's interview transcripts and clearly explained my rationale for including or excluding each device in my analysis (shaded boxes represent devices that were excluded).

*Table A2: External evaluative devices identified for analysis in the current study*

<b>External Evaluative Device</b>	<b>Examples from the Current Study's Interview Transcripts</b>	<b>Rationale for inclusion/ exclusion in the current study</b>
The narrator <i>explicitly</i> says what the point of the story/segment is.	<i>That was hopeless that was.</i> <i>They weren't much help at all.</i>	This is the most obvious and overt form of evaluation. It is therefore essential for inclusion in analysis.
An <i>evaluative remark</i> made by the narrator at the time of the event.	<i>I used to be like "Aagh"!</i> <i>I thought, "for God's sake, give us a break"</i>	This gives a clear indication of the thoughts and feelings of participants at the time of the event.
The narrator <i>quotes himself</i> addressing other characters.	<i>I had a go at them and said</i> <i>"Excuse me, what? Who?</i> <i>Which one are you?"</i>	The use of direct speech is useful in identifying participants' recalling of their views, thoughts and feelings from the time of the event.

An interpretive evaluative remark is made by any other character in the story.	<i>She said "I don't know how you put up with him".</i>	Speech is used by my participants to represent other people's evaluations of events, and is often used to validate their point.
A narrative action is evaluative (i.e. what the person did rather than what they said).	<i>I was going go flying like a... elephant at them...</i>	The salience of this evaluative device is explained by the idiom 'actions speak louder than words'.

Table A3: Internal evaluative devices identified for analysis in the current study

Internal Evaluative Device		Examples from the Current Study's Interview Transcripts	Rationale for inclusion/ exclusion in the current study
Intensifiers serve to add emphasis to a specific event.	Modifiers (adjectives, adverbs)	<i>It has helped him <u>tremendously</u>.</i>	Both participants used these devices to add emphasis, so I applied them as criteria for identifying evaluative clauses in relation to Research Question Two.
	Quantifiers (how much or how many)	<i>He had such, such a lot going on.</i>	
	Wh- exclamations	<i>"Why on earth am I bothering, even attending this meeting?"</i>	
	Repetition	<i>He was special to me and he is still special... He was special, he was special from the start.</i>	
	Heightened stress/emphasis	-	These phonological and paralinguistic features were not transcribed.
	Vowel lengthening	-	
	Intonation and pitch	-	
	Gestures	-	Gestures could not be included in analysis as participants were not video-recorded during the interview.

Comparators are used to compare events that did not happen with those that did	Negatives (the non-happening of something that was expected to happen)	<i>...especially when it comes to referrals – and they don't do them.</i>	These are central to the current study, in which participants often reflect upon possible alternatives to what actually happened.
	Modal verbs (should/could/would)	<i>Maybe they <u>could</u> have thought, 'maybe we need to look into this'.... I think it <u>should</u> have been picked up then.</i>	
	Questions embedded in the action	<i>What do you do? How do you deal with that?</i>	Sometimes participants used rhetorical questions to address me (as interviewer).
	Imperatives	<i>I said, "no, you will not keep him on the list"</i>	These are rarely used by participants, but were still included in analysis where relevant.
	Future tenses	<i>'You <u>will</u> see a social worker', which we did.</i>	
	Comparatives and superlatives (adjectives and adverbs)	<i>He was my <u>biggest</u> bane of my life.</i>	
Extension (joining together two events in a single clause)		-	Omitted due to the complex syntactical analysis required. Furthermore, speech rarely contains the same grammatical format as formal written language, making identification of syntactical features more challenging.
Explications/ explanations (causal subordinate clauses embedded within an independent clause)		-	

**Appendix 8: Extracts of ‘clean’ transcripts**

As described in Figure 1, the ‘cleaning’, condensing and smoothing of narratives occurred throughout the analysis. The extracts below present examples of the initial transcription stages. My initial analysis involved highlighting segments of event narrative (yellow) and experience narrative (blue).

Extract from Maria’s interview

**Extract from Cathy's interview**

[REDACTED]



## Appendix 9: Extracts from Maria and Cathy's interviews re-storied narratives

Having highlighted sections within the main interview transcripts as event narratives and experience narratives, I began to re-story the events in chronological order, and make preliminary comments and interpretations. At this stage, I began 'condensing' the narratives to capture the content and meaning as succinctly as possible, based on the guiding questions in Appendix 7.

Table A4: Extract from analysis of Maria's event narrative

Temporal Sequence (Chapters)	Key Event Narrative	Significance and Relevance to Mainline plot	
		Maria's Interpretation	My Interpretation
<b>Chapter 1:</b> Pregnancy – didn't like to touch (pre-birth)	<ul style="list-style-type: none"> <li>I do think he showed signs of being autistic before he was even born</li> <li>he didn't move and he didn't like to be touched</li> <li>pregnancy didn't know any different, but looking back now, I know, there were probably signs that he didn't like to be touched even right from the beginning.</li> </ul>	<ul style="list-style-type: none"> <li>My second pregnancy was totally different. Totally and utterly different.</li> <li>It was really funny like that. In hindsight – hindsight's a wonderful thing.</li> <li>knowing what we know now would be... sort of...</li> <li>I think knowing what I know now, all his traits from a baby were so autistic. He was an autistic nightma- he was an autistic dream, I think, but it just wasn't recognised whatsoever</li> </ul>	<p>Early autism symptoms in hindsight</p> <p>Sense of knowledge/awareness in hindsight</p>
<b>Chapter 2:</b> Health visitors – asked for help (birth to 3 years)	<ul style="list-style-type: none"> <li>Then it was the health visitors</li> <li>I didn't possibly have the best role model with my mother</li> <li>So I would always ask for help – especially on the parenting side.</li> <li>Imagine having an 'ever-ready bunny' running around the place</li> <li>he was like a Tasmanian devil - running round the place. Extremely energetic.</li> </ul>	<ul style="list-style-type: none"> <li>That was the best one.</li> <li>That was hopeless that was.</li> <li>They weren't much help at all.</li> <li>I have someone that turns round and tells you it's your fault that your child's just the way they are.</li> <li>People just didn't pay any attention to what I was telling them</li> <li>I had to have a very big decision about whether to have another child, because the thought of having two like him... At that time we didn't know what it was. The thought of having two of them like him running around would be a nightmare. The looney bin would've been my new home [laughing] because he was literally that active.</li> </ul>	<p>Behavioural difficulties attributed to for poor parenting</p> <p>Feeling blamed</p> <p>Decision about having another child – emphasises everyday challenges of raising a child with (undiagnosed) ASC</p>

Table A5: Extract from analysis of Cathy's event narrative

Temporal Sequence (Chapters)	Key Event Narrative	Significance and Relevance to Mainline plot	
		Cathy's Interpretation	My Interpretation
<b>Chapter 4:</b> Primary Years: Infants (4-8 years)	<ul style="list-style-type: none"> <li>• <i>Jake started school and then, this is when the Tourette's started.</i></li> <li>• <i>When he was about 6 or 7, we noticed a lot of habits... blinking was a main one and facial things where he might twitch his nose or perhaps do something with his mouth. He did noises... he used to flick his ears... he would pick the one foot up and it would rub it down the back of his leg like that, and then the same with that one, and that was how he walked.</i></li> <li>• <i>As he got older, he did say that he was able to control it... he would get to the point where he said he used to feel like his head was going to explode and he would just have to release it</i></li> <li>• <i>There's a question mark now as to whether that was Tourette's or whether it was actually symptoms of the autism. I've asked the question, but you don't really get a definite black and white answer to it. So I'm not really sure whether he...</i></li> <li>• <i>In his very first year at Primary school, they thought that he was dyslexic... because his writing had all the symptoms and signs... so again he had special help for that, but then that never got mentioned later on.</i></li> </ul>	<ul style="list-style-type: none"> <li>• We just thought it was nervous – again, you speak to all other parents and they say, “oh mine blinks their eyes, it is just a habit, it is just a child habit, it is nothing to worry about”, so you just accept that for a while</li> <li>• That became quite annoying [laughing] and worrying because you think well, why is he doing it...</li> <li>• He got teased at school, he got called the name “blinky” because obviously they picked up on that.</li> <li>• I think <u>if they may have questioned it more</u>, they surely know all the child... <u>they know a lot more than me...</u> maybe they could have thought maybe we need to look into this, maybe there's something else other. They just listened to what I said and sent us away.</li> <li>• But I often wonder now, <u>'was that the key time when it could have been further investigated?'</u> Because there were other signs had I have been asked about. <u>But there was no relevance to me to bring it up because...</u></li> <li>• It got missed.</li> </ul>	<ul style="list-style-type: none"> <li>• Dissatisfied with 'Tourette's Syndrome' diagnosis and lack of support (i.e. just waiting for it to go away!)</li> <li>• Sensory processing differences? (such as visual/auditory filtering)</li> <li>• Possible time when Jake's ACS could have been identified, 'was that the key time when it could have been further investigated?'</li> <li>• Onus on professionals: 'they know a lot more than me' and 'there was no relevance to me to bring it up'.</li> </ul>

## Appendix 10 - Analysis of event narratives - Maria and Cathy (RQ1)

These tables present the key event narrative for each participant, following the stages described in Appendices 8-9.

Table A6: RQ1 - Participant 1: Maria and Kyle

Timescale	Key Event/Memory	Significance to Mainline Plot (How do these events help to explain the timing of the diagnosis?)
<b>Chapter 1:</b> Pregnancy – didn't like to touch (pre-birth)	Kyle was an unusual pregnancy, 'he didn't move and he didn't like to be touched', which only came to light because Maria's 'second pregnancy was totally different'.	With hindsight, Maria reflects on Kyle's early signs of ASC, 'knowing what I know now, all his traits from a baby were so autistic but it just wasn't recognised whatsoever'.
<b>Chapter 2:</b> Health visitors – asked for help (birth to 3 years)	Maria's first concerns related to Kyle's behaviour, describing him as an 'ever-ready bunny' and 'a Tasmanian devil'.	Maria asked for parenting support, but felt blamed for Kyle's difficulties: 'I have someone that turns round and tells you it's your fault that your child's just the way they are'.
	Maria notes early signs of ASC in hindsight, 'sensory things, textures...' His pattern of language, physical development and his self-help skills were unusual, 'his speech was late, [but] came all of a sudden... he doesn't do in-between stages'.	Maria notes the presence of developmental concerns from an early age, which she was aware of at the time, but did not 'know about' ASC. She may have reinterpreted some of her early concerns as 'sensory issues', in light of the ASC diagnosis.
<b>Chapter 3:</b> Nursery / Early Years (3-5 years) 'Possible autism'	In response to Maria's concerns, Kyle received early professional involvement, '[I] explained my concerns [and] within a very short space of time, he got onto the early years' team'.	Maria's emphasis on the short time frame serves to highlight the severity of her concerns and her perception of Kyle's high level of additional needs at the time.
<b>Chapter 4:</b> Dr A, ADHD, Dyspraxia (age 5-ish)	Maria recounts a missing report: 'I had a psychologist's report that I never received, which had the possibility that he was autistic. Or autism was mentioned, but I never got the report'.	Maria revisits this key event at the end of the interview, highlighting her interpretation of its significance. She considers that ASC could have been identified at this point: 'if I had researched it at that point, he had all the symptoms', but she considers it was 'missed'.
	Other diagnoses were explored, '[Doctor A] suggested that we thought it was ADHD... possibly... and dyspraxia. . [ADHD was] just explored, so I never had a formal diagnosis that was signed off. He was diagnosed [with dyspraxia] at a later stage'.	Maria seems to be making sense of alternative diagnoses. She describes her understanding of symptom overlap, 'it plays into the other stuff', and her lack of clarity, 'diagnoses sort of things'. She reports that she didn't 'know about' autism, which I interpret

		to mean that she was not able to suggest exploring it at this stage.
	Maria reflects upon how professionals to date did not take a full developmental history, 'They never asked about his pregnancy, they never asked about his development', but that this was the first thing the EP did. She suggests that a past professional (unknown) dismissed her concerns, concluding that 'he is doing quite normally' after only observing him for 20 minutes.	This indicates Maria's views about how developmental problems should be investigated and explored: holistically and comprehensively. Implicitly, she suggests that professionals should have enquired about Kyle's developmental history. She also implies that her concerns should not have been dismissed, particularly only on the basis of a single 20-minute observation of Kyle.
<b>Chapter 5 –</b> Social Services, S clinic, help (age 5)	Social services misinterpreted Kyle's sensory differences (involving his messy hands and removing his clothes) and a hygiene and social care issue.	Maria defends her parental knowledge and experience, 'I knew... what to expect for a child of that age' and 'I am more consistent than a lot of parents'. Underlying this, she is reiterating that her parenting is not to blame.
<b>Chapter 6:</b> Working at school, finding a support system (Age 6 – present)	Maria notes that some members of the family (mainly her mother-in-law) did not 'accept' that there were problems: 'certain parties that wouldn't accept that there was a problem'.	Maria does not directly say whether this influenced the timing of the diagnosis, but it may have had an influence.
<b>Chapter 7:</b> Transition primary – secondary (9-11 years)	Maria reports that Kyle was well supported at primary school. He had good relationships with staff and his 'needs' were understood and met, without the need for a diagnosis: 'We hadn't needed any formal paperwork because where he went to school, they supported him extremely well'.	It seems that being so well supported at primary school may have delayed the need for a diagnosis in Kyle's case. Kyle's parents 'knew what the difficulties were' and understood his needs well, but decided to seek a formal diagnosis so that others (perhaps school staff or Kyle's peers) would recognise and support his needs at secondary school.
<b>Chapter 8:</b> Diagnosis, useless doctors (10-12 years)	Maria reports that the diagnostic process itself took approximately two years, and that she had had been waiting for 9 months before that.	Maria interprets delays in the diagnostic process, due to repeating herself over 3 meetings with the paediatrician, 'I had gone through 7 months and nothing had been achieved', and his lack of information sharing: 'he hadn't sent any information to anybody'.
	Maria states, 'I had to do all the paperwork... I got all the paperwork put up together by the Wednesday. By Thursday night, I was dropping it	A strong theme for Maria is that she has taken the lead. She contrasts the 9 months of waiting and 7 months of 'achieving nothing', with her rapid

	through the door. It went to panel on Friday and got diagnosed’.	collation of paperwork leading to the diagnosis being made by the panel: ‘within a week, I had got him diagnosed’.
	The ‘realisation’ for Maria occurred through working (as a TA) with a young person with Asperger’s syndrome: ‘I knew later on... exactly what it was’.	This marks the first parental recognition of autism-specific symptoms: ‘The links between this young man and Kyle were the social cues’. She doesn’t say exactly when this realisation occurred.
<b>Chapter 9:</b> Breakdown level (13 years)	Due to Kyle’s challenging behaviour, Maria describes ‘getting proper help’ from the EP.	In slight contradiction to her earlier claim, ‘I got him diagnosed’, Maria describes the EP as the one who ‘diagnosed him’, perhaps in reference to their joint compilation of the relevant paperwork.

*Table A7: RQ1 - Participant 2: Cathy and Jake*

<b>Timescale</b>	<b>Key Event/Memory</b>	<b>Significance to Mainline Plot</b> (How do these events help to explain the timing of the diagnosis?)
<b>Chapter 1:</b> Special baby (Pre-birth/ pregnancy)	Cathy recounts: ‘I had been told several times that I couldn’t have children... he was special from the start’.	Jake being ‘special from the start’ seems to be a pertinent theme for Cathy. Looking back, she expresses a sense of vindication that her parenting is not to blame.
<b>Chapter 2:</b> Early years (Birth- 2.5 years)	Cathy reflects on signs of ASC in hindsight, including Jake’s unusual interests, preference for non-fiction and rote-learning: ‘there were signs then with the autism which I only can see now, looking back’. She expressed no concerns at the time, ‘it wasn’t anything that alarmed me’.	Jake’s parents normalised his ‘comical ways’ and were not concerned, but Cathy now makes sense of Jake’s unusual behaviours in light of the ASC diagnosis. She portrays him as ‘different’, but not ‘disabled’: no distress or dysfunction was apparent. Cathy hints that at the time she didn’t ‘notice’, perhaps due to lack of experience of typical development (Jake is an only child) and/or awareness of ASC.
<b>Chapter 3:</b> New family unit (2.5 – 4 years)	Cathy reflects on Jake’s unusual preference for real tools: ‘My husband used to give him a drill, screws and a piece of wood’.	At the time, Cathy and her husband were not concerned, but Jake’s preference for real tools rather than toys and symbolic play, may have been a possible early sign of ASC in hindsight.
<b>Chapter 4:</b> Primary Years: Infants (4-8 years)	A diagnosis of ‘Tourette’s Syndrome’ was made based on Jake’s ‘habits’ (blinking, facial twitches and flicking his ears). Cathy reflects on the validity of this diagnosis: ‘There’s a question mark now as to whether that was	These behaviours could be interpreted as sensory processing differences, such as visual/auditory filtering. Kyle’s description of ‘his head feeling like it would explode’ could be interpreted as ‘sensory overload’. Here, Kyle seems to begin to show self-consciousness about being ‘different’. At

	Tourette's or whether it was actually symptoms of autism'. She highlights the ambiguity: 'you don't really get a definite black and white answer'.	the end of the interview, Cathy reflects 'was that the key time when 'it' could have been further investigated?' She places the onus on professionals to have done this: 'they know a lot more than me' and 'there was no relevance to me to bring it up'.
<b>Chapter 5:</b> Juniors (8-11 years)	Cathy recalls that further issues were 'picked up' by staff at the junior school. Here, the support offered was primarily related to 'mobility' concerns (gross and fine motor skills).	Although not autism-specific, Cathy understands her initial concerns as contributory factors in Jake's ASC diagnosis: '[those] issues have since become evidence of the condition'. She shares her changed understanding: 'That was all a symptom which we didn't know at the time'.
<b>Chapter 6:</b> Development (11-13 years)	This chapter marks the discovery of Jake's strengths and academic potential. Jake channelled his 'special interest' (computers) positively to achieve something that was considered 'worthwhile' by school staff and parents. Cathy describes him becoming 'obsessed' with his GCSEs.	Cathy seems surprised by Jake's capabilities, 'all of a sudden... he was achieving grades' and describes her raised aspirations: '[he] wasn't what we thought he was going to be'. She reflects further on signs of ASC in hindsight: his tendency towards solitude and project-work, 'he was always happy just doing his own thing', and his better social relationships with teachers: 'he doesn't get on with people his own age really'.
<b>Chapter 7:</b> A traumatic time (13-15 years)	Cathy recounts: 'From 13 to 15, we started hitting a lot of problems, family issues'. She considers the role of hormonal influences on his behaviour, 'it was probably hormonal', but considers the situation was worse than typical families: 'it doesn't come across how bad it was'.	This is the first time that Cathy seems to express any real concern. Interestingly, at this stage, she attributes this to 'family issues' and arguments, rather than to Jake himself. She describes the 'hidden' nature of Jake's difficulties, 'they don't really see the problems', and the lack of understanding from friends and family members, who normalised Jake's behaviour: 'he is just a teenager... ours are the same'.
	Cathy describes Jake's frequent lateness for school. She describes a 'big argument' in the family, resulting in Jake moving in with his biological father. She recounts how Jake was unable to reflect upon what had happened, despite her request: '[I said] "We have got to talk... you have got to understand what you've done"... and it just turned into more arguments'.	In hindsight, Cathy re-framed the arguments about Jake's lateness, in light of him not understanding social rules, 'but he can't see that'. These hidden difficulties were not understood by the school, who admitted: 'We overlook Jake because he is a good student'. With hindsight, Jake's inability to understand 'what he had done', Cathy now sees as part of his ASC (poor social understanding), 'looking back, it was part...' This phase marks the build-up of a family crisis point: 'We [had] had enough of

		it' and perhaps the catalyst for seeking help.
<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	Cathy is concerned about Jake's 'state of mind' and possible depression. She portrays his unemotional and insensitive response to the family dog dying: 'when you see that someone is upset, you think "they're obviously not in the mood"... but Jake didn't pick up on it'.	At the time, Cathy didn't understand Jake's behaviour and comments, so she concluded, 'I have reared a monster', but in hindsight, she seems to understand Jake's differences in emotional processing and his difficulties reading social situations as part of his ASC.
	Cathy requested help from the school liaison officer: 'We are having all these problems at home'. Initially, she did not see the problems, but then 'she did see a side to him which I don't think she had realised'.	Cathy's concerns prompted her request for support for the family, to 'sort something out for us', rather than seeking a diagnosis or support for Jake specifically. The difficulties again seem to be hidden initially, with the liaison officer saying, "I didn't realise because he is so well mannered at school".
	Cathy suggests to the liaison officer that Jake may have a condition which explains the family problems: 'It was just a flippant comment. I said, "Do you think that there is some OCD?"'	This marks the 'realisation' and key turning point for Cathy: 'The penny just seemed to drop... we realised, "hold on a minute, could there be a condition rather than just a behavioural problem?"'
	Cathy researched various diagnoses/conditions. Asperger's syndrome seemed to be a 'strong fit': 'I felt as though somebody must have written it about my son and about my life'.	This marks Cathy's 'realisation' that ASC is a strong possible explanation for Jake's presentation.
	Cathy reflects upon how, at 16, she needed to gain Jake's consent for all referrals.	Cathy considers that Jake's consent delayed the process, '3 weeks went by and they [school staff] still hadn't got the form filled in or signed by Jake'. She reflects upon how his consent may have prevented the entire referral and therefore diagnosis: 'If he had said, "no"... there wouldn't have been a damned thing I could do about it'. As a result, she admits to the hidden agenda of the referral: 'Jake was under the impression that it was to do with family issues... but I knew it was because we thought he had got Asperger's'.
	Cathy recalls waiting 3 weeks for Jake to sign the referral form, then a further 2 months for the appointment: 'We couldn't go until the April, so we had to wait'.	This highlights Cathy's perception of delays in the referral process itself.

	<p>In the initial appointment, the social worker dismissed the idea of Asperger's based on surface assumptions, 'he can hold a conversation totally well with me' and her gathering 'stupid details which aren't anything to do with the problem'. She suggested, 'I think there may be a personality disorder', but changed her mind, based on one 'blunt' comment that Jake made and after reading Cathy's notes about his developmental history.</p>	<p>I found the social worker's initial conclusions surprising, as I would consider this to be beyond the professional role and knowledge of a social worker. This experience also further emphasises the sometimes 'hidden difficulties' of ASC and the risk of diagnoses either being missed or inaccurately suggested, due to 'snap judgements' made by professionals based on brief and superficial information.</p>
<p><b>Chapter 9:</b> Moving forward (17 years plus)</p>	<p>Cathy reflects on the timing of the diagnosis. She revisits two time-points when she thinks ASC could have been identified. Firstly: 'I think it could have been picked up at primary school, but I can understand why it wasn't'; and secondly: 'It should have been picked up at the hospital... I think they should have investigated other things as well'.</p>	<p>In seeking to make sense of the whole story, Cathy attributes the realisation and identification of ASC to chance ('a fluke') and repeats 'it would have been so easy' [for it to have been missed]. Cathy's final poignant comment 'we may never have known' indicates her perception that Jake's later diagnosis only occurred because of a complex set of 'chance' circumstances, within which if it was different at any stage, ASC may have been 'missed' completely.</p>



## Appendix 11: In-depth analysis matrices for RQ2 – Maria and Cathy

### Maria and Kyle (Analysis for RQ2)

Table A8: Maria's experience narrative: Pre-diagnosis

Timescales	Maria's Experience Narrative	My Interpretation and Commentary <i>What is the impact of the later diagnosis?</i>
<b>Chapter 2:</b> Health visitors – asked for help (birth to 3 years)	<ul style="list-style-type: none"> <li>• <i>Imagine having an 'ever-ready bunny' running around the place.</i></li> <li>• <i>He was like a Tasmanian devil - running round the place. Extremely energetic.</i></li> </ul>	Maria expressed early concerns about Kyle and the challenges of coping Kyle's behaviour, using the imperative "imagine..." for me to visualise her experience. She also suggested that there was a lack of explanation for Kyle's behaviour, "we didn't know what it was".
	<ul style="list-style-type: none"> <li>• <i>That was <u>the best one</u>.</i></li> <li>• <i>That was <u>hopeless</u> that was.</i></li> <li>• <i>They <u>weren't much help at all</u>.</i></li> <li>• <i>I have someone that turns round and tells you <u>it's your fault</u>.</i></li> <li>• <i>People <u>just didn't pay any attention</u> to what I was telling them.</i></li> </ul>	Maria reported that the health visitor team were "hopeless" and not "much help at all", describing this period sarcastically as "the best one". She describes feeling blamed when she asked for help and feeling that her concerns were not acted upon.
	<ul style="list-style-type: none"> <li>• <i>I had to have <u>a very big decision about whether to have another child... At that time we didn't know what it was</u>. The thought of having two of them like him running around would be a nightmare.</i></li> </ul>	Maria repeated the implied difficulty of 'not knowing' or having an adequate explanation for Kyle's behaviour. This could have impacted on Maria's family planning decisions.
<b>Chapter 3:</b> Nursery / Early Years (3-5 years) 'Possible autism'	<ul style="list-style-type: none"> <li>• <i><u>Within a very short space of time</u>, then he got onto the early years team.</i></li> <li>• <i>He started school in the <u>January and by the time we got to Easter</u>, we had the Early Years team involved with him.</i></li> </ul>	Maria reiterates her early parental concerns and uses time details to emphasise how soon services/ professionals became involved with Kyle. Maria uses the professional involvement to verify and validate her early concerns and her perception of Kyle's high level of need.
<b>Chapter 4:</b> Dr A, ADHD, Dyspraxia (age 5-ish)	<ul style="list-style-type: none"> <li>• <i>This is where I got <u>let down</u>... because I had a psychologist's report that I never received, which had the possibility that he was autistic. Or autism was mentioned, <u>but I never got the report</u>.</i></li> <li>• <i>That made me <u>really angry</u> that I never received it [the report] at that point. I was <u>f</u> I was <u>more upset</u> and <u>disappointed</u> at that point.</i></li> </ul>	Maria narrated that she felt "let down" by never receiving the EP report and shares her emotional response to discovering that she had not received the EP report: "really angry", "upset" and "disappointed". She directly reflected upon the impact of this, using comparators to describe how things would have "made more sense" and "been a lot easier", indicating that an earlier diagnosis may have led to

	<ul style="list-style-type: none"> <li><i>If I had known, if I had had that piece of paper, a lot of that <u>would have made sense</u> and then <u>that bit wouldn't have happened</u> and then <u>this bit would have been a lot easier because the support would have been a lot easier</u> because I would have had him <u>statemented</u>.</i></li> </ul>	improved understanding and/or additional support.
Chapter 5 – Social Services S clinic, help (age 5)	<ul style="list-style-type: none"> <li><i>They were concerned about his hygiene 'cause he had a habit of hands..., <u>as little boys do</u>, smelly sort of things. We'd dealt with an awful lot of <u>issues with Kyle – sensory and whatsoever</u>.</i></li> <li><i>I was <u>extremely annoyed</u> at them.</i></li> </ul>	Maria recounted the time that school staff misunderstood Kyle's sensory issues as a hygiene and social care issue. This led to a strong sense of intrusion and concern about her reputation among work colleagues, as the social worker worked at the same school as Maria. Maria directly stated that she felt "extremely annoyed" at them.
	<ul style="list-style-type: none"> <li><i>...<u>Not being believed</u>.</i></li> <li><i>...rather than going, "oh no, <u>that's not a problem</u>, he is doing quite normally" [after] being with the child for <u>just 20 minutes</u> in a room</i></li> <li><i>It is <u>like being judged</u> that it is <u>your fault</u> that this is going on and it is <u>your problem</u>.</i></li> <li><i>You feel "<u>why has no-one ever taken me seriously?</u>"</i></li> </ul>	Maria reported feeling like she wasn't believed, or taken seriously, and that professionals dismissed her concerns, directly quoting them: "oh no that's not a problem". She repeated her sense of feeling blamed and judged.
	<ul style="list-style-type: none"> <li><i>When I <u>had my breakdown</u> on that one day, I contacted the child and disabilities team.</i></li> <li><i>They wanted to send me back to S clinic. I said "<u>Do not bother sending me to that one</u>".</i></li> </ul>	Maria discloses that she experienced a "breakdown", which signifies the negative impact of parenting a child with undiagnosed ASC on Maria. At this stage she asked for further support, but narrates her imperative from the time, "do not bother sending me..." to emphasise how previous 'support' was not perceived to be supportive: perhaps due to the general focus on 'parenting skills' rather than being tailored to ASC specific parenting support.
Chapter 6: Working at school, finding a support system (Age 6 – present)	<ul style="list-style-type: none"> <li><i>We <u>went through four child-minders</u> before he found a suitable one.</i></li> <li><i>People just <u>couldn't cope with him</u>.</i></li> </ul>	Maria further emphasises Kyle's complex needs and challenging behaviour, verifying this with the difficulties finding a childminder who could "manage him".
Chapter 7: Transition	<ul style="list-style-type: none"> <li><i>At that point, he <u>hadn't needed</u>, we <u>hadn't needed</u> any formal paperwork</i></li> </ul>	Maria described her perceived 'need' for diagnosis at this stage, and wanting

primary – secondary (9-11 years)	<p><i>because where he was, where he went to school <u>they supported him extremely well in that aspect.</u></i></p> <ul style="list-style-type: none"> <li>• <i>Year 6 we <u>needed a formal diagnosis</u> from, we sort of needed a formal one to get him through to know what paperwork for school and statementing and whatever else was required.</i></li> </ul>	it to 'be formal' and 'on paper'. She believed that the diagnosis would be necessary or required to "get him through" secondary school.
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Table A9: Maria's experience narrative: Diagnosis phase

Timescales	Maria's Experience Narrative	My Interpretation and Commentary <i>What is the impact of the later diagnosis?</i>
<b>Chapter 8:</b> Diagnosis, useless doctors (10-12 years)	<ul style="list-style-type: none"> <li>• <i>From [age] 10 to 12... that's <u>how long it took us to get the diagnosis.</u></i></li> </ul>	Maria implies that the time to "get" the diagnosis was too long.
	<ul style="list-style-type: none"> <li>• <i>Diagnosis and <u>incompetency</u> I think is ... or shall I say <u>useless, useless</u> doctors. He was my <u>biggest bane of my life in that one</u> (pointing to Doctor's name)</i></li> <li>• <i>We were <u>really badly let down by this gentleman</u></i></li> <li>• <i>I <u>ripped hell out of him.</u></i></li> <li>• <i>He had met our SENCO at that point and <u>she found him arrogant.</u></i></li> <li>• <i>He was just <u>a nightmare.</u></i></li> <li>• <i>So basically a feeling of <u>anger</u> at him that he thought he was <u>mightier than God [and] that everyone else should do the paperwork.</u></i></li> </ul>	Maria feels very strongly about this doctor, using the superlative 'biggest bane of my life' and describing him with powerful adjectives, 'incompetent', 'useless' and 'a nightmare'. She validates her view by reporting that the SENCO also found him 'arrogant'. The reason for this strong view relates to her perception that he thought 'everyone else should do the paperwork'. Maria describes that this experience left her feeling 'angry' and 'badly let down'. She recounts her actions that she 'ripped hell out of him'; in narrative terms, she positions herself as protagonist in causing the doctor to be 'running scared' and making an example of him in front of his student doctor.
	<ul style="list-style-type: none"> <li>• <i>It was more <u>anger.</u></i></li> <li>• <i>I have been through it with two people and the third person is asking me the same information, <u>like a broken record.</u></i></li> <li>• <i>It was like "why am I having to tell you this again?"</i></li> <li>• <i>All he had sent was an A4 sheet every time it had gone to panel, so <u>how can anyone do a diagnosis from that?</u></i></li> <li>• <i><u>That really narked me.</u></i></li> </ul>	Maria seems to express frustration, which she describes as 'anger' and feeling 'narked', as a result of having to repeat the same information several times. In response to the lack of information shared by the doctor, her question, 'how can anyone do a diagnosis from that?' serves to further highlight her frustration.
	<ul style="list-style-type: none"> <li>• <i>So as a result, I had to do <u>all the paperwork, run around all the paperwork.</u></i></li> </ul>	Again, Maria positions herself as 'taking the lead' in doing all the paperwork, and co-ordinating professionals and information-sharing. There is an increasing

	<ul style="list-style-type: none"> <li>• <i>It did feel like I was in a tornado.</i></li> <li>• <i>The only way you get anything done is <u>by you taking the lead and go right</u> – this needs to be done.</i></li> </ul>	sense of repetition and going round in circles, which Maria describes figuratively, 'like I was in a tornado'.
	<ul style="list-style-type: none"> <li>• <i>It was the <u>anger</u>, the fact that I had gone through <u>7 months</u> and nothing had been achieved whatsoever and I know these <u>processes take so long</u>, I am <u>prepared for that</u>, but <u>nothing has been done</u> and it has taken me one meeting, it has taken me one meeting, a couple of days to get all his paperwork together, so they have got the paperwork to prove – to back up what we have got, and it was fine, and <u>within a week</u>, I <u>had got him diagnosed</u>.</i></li> <li>• <i>It was just <u>he was messing around</u> and that was <u>pure anger</u>.</i></li> </ul>	Maria continues the lexical repetition of her emotion, 'anger', as well as adding intensifiers 'really angry' and 'pure anger'. Maria repeats the time frame '7 months', which serves to mark this period as a time of waiting. At the resolution of this narrative episode, Maria contrasts this time frame with 'within a week, I had got him diagnosed'. Maria acknowledges that 'these processes' can be lengthy, but that when she realised 'nothing ha[d] been done', she became pro-active again in organising the relevant paperwork. Perhaps this is because of the later diagnosis creating an increased sense of urgency.
<b>Key turning point:</b> Diagnosis of autism	<ul style="list-style-type: none"> <li>• <i>(Sigh) <u>Gratification</u> that I had actually, not that I was right, that <u>it was confirmed that I was right</u>. I <u>knew what it was</u> and that <u>at least I had a piece of paper</u> that if anyone turned round and said, "what is his diagnosis?", I could turn round and say <u>he is definitely on the autistic spectrum</u>, he has got traits of ADHD and he is dyspraxic.</i></li> </ul>	The turning point for Maria was receiving the actual diagnosis of autism. She describes her 'gratification' that the diagnosis was confirmed and that she had been right. I interpret that she seems reassured by receiving the formal diagnosis, both in terms of her own understanding, 'I knew what it was' and well as to explain Kyle's needs to others, 'at least I had a piece of paper'.

Table A10: Maria's experience narrative: Post-diagnosis and general reflections throughout the interview

<b>Timescales</b>	<b>Maria's Experience Narrative</b>	<b>My Interpretation and Commentary</b> <i>What is the impact of the later diagnosis?</i>
<b>Chapter 9:</b> Breakdown level, problem stealing behaviour (13 years)	<ul style="list-style-type: none"> <li>• <i>That would come down to <u>breakdown level</u>. [He was] 13 I think at that point. We had problems with stealing, behaviour <u>causing major upsets</u>.</i></li> <li>• <i>I was having meetings at the school and I broke down in tears. I was out in reception and I just went, <u>everywhere</u>, I had just had enough.</i></li> </ul>	Maria describes this time as 'breakdown level', in reference to her sudden emotional breakdown at school. From her description of her actions, 'I broke down in tears' and her phrase, 'I just went, everywhere', I interpret her perceived vulnerability and sense of feeling out of control. Maria seems to have reached a crisis point - 'I had just had enough'. At this

	<ul style="list-style-type: none"> <li>• <i>The only way we did it by... was getting proper help with [EP] dealing with him, because <u>he diagnosed him, he dealt with the school...</u> and I was meeting [him] here on a weekly or monthly basis and putting on techniques to try and get him down.</i></li> <li>• <i>[EP] is my angel, literally.</i></li> </ul>	<p>point, she received 1:1 help from the EP to support with behaviour strategies. In contrast to previous lexical terms used throughout, such as 'nightmare' and 'bane of my life', Maria describes the EP as 'her angel'.</p>
<b>Nadir experience:</b> Too much too handle, deal with cancer, deal with behaviour (13 years)	<ul style="list-style-type: none"> <li>• <i>Because that was <u>dealing with</u> obviously the cancer, <u>dealing with</u> my husband and everything else and the little one.</i></li> <li>• <i><u>Too much to handle.</u></i></li> <li>• <i>Dealing with behaviour, <u>still working</u> and <u>still running round</u> and <u>still doing everything else.</u></i></li> </ul>	<p>Maria describes this as the worst time overall. She repeats the phrases 'dealing with...' and 'still...' to show how she was dealing with a lot, whilst trying to carry on as normal. Interestingly, despite her earlier comments that 'not knowing' was a source of stress, Maria does not indicate that the diagnosis served to reduce this, due to other arising stressors, including new challenges with Kyle's behaviour.</p>
<b>Theme</b>	<ul style="list-style-type: none"> <li>• <i>Being a <u>bulldog</u> [laughs]. My son would call me a bulldog because I need to get something done.</i></li> <li>• <i>Basically just be a bulldog because I have literally <u>fought tooth and nail over most things.</u></i></li> <li>• <i>Yeah, <u>stubborn bulldog.</u> They just call me the bulldog for that reason.</i></li> </ul>	<p>When asked to identify a theme for the story, Maria chose to reflect on her own identity. Her theme, and description of herself, 'stubborn bulldog', connotes a sense of strength and 'fighting', which have been themes throughout.</p>
<b>Title</b>	<ul style="list-style-type: none"> <li>• <i>'<u>Endurance.</u>' Endurance of the third kind... because you just can't give up at any point.</i></li> <li>• <i>It's mental ability. It is a mental thing, it is not a physical thing.</i></li> <li>• <i>You can have moments where you think "<u>Can I really do this?</u>"</i></li> <li>• <i>You have got to do such short steps so it is <u>an endurance process</u>, it is like running a marathon mostly.</i></li> </ul>	<p>When asked to think of a title, Maria chose, 'endurance', which she explained captured her perception of not being able to give up, despite questioning her own ability, 'can I really do this?' She describes the whole experience as 'an endurance process... like running a marathon'.</p>
<b>General Post-diagnosis Reflections</b> (no particular timescales)	<ul style="list-style-type: none"> <li>• <i>Kyle has had a habit... he could be a very good mountain climber when he is older because he has been down every path and <u>every pothole</u> and he will come back up.</i></li> </ul>	<p>Maria uses metaphor to explain her perception that Kyle seems to have a 'habit' of going down every pothole (problem or hurdle), but that he will "come back up" (recover). Staying with this metaphor, I interpret that Maria believes that her 'journey' has been a 'bumpy ride'.</p>

	<ul style="list-style-type: none"> <li>• <i>The trouble with having to parent with a child with any disability, is <u>you become horrible!</u> [laughs] Because you have to <u>fight for every single thing</u> because people will tell you that you're doing things – especially when it comes to referrals – and <u>they don't do them.</u></i></li> </ul>	Maria expresses the cynical view that 'people' (referring to professionals) don't do things, particularly referrals. She uses the language of "having to fight" and jokingly describes the effect of this on her own identity, "you become horrible!"
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### Cathy and Jake (Analysis for RQ2)

Table A11: Cathy's experience narrative: Pre-diagnosis

Timescales	Maria's Experience Narrative	My Interpretation and Commentary <i>What is the impact of the later diagnosis?</i>
<b>Chapter 2:</b> Early years (Birth- 2.5 years)	<ul style="list-style-type: none"> <li>• <i>He was a comical toddler, he did comical things, but that was just him, you know, I don't know, <u>it wasn't anything that alarmed me at the time.</u></i></li> <li>• <i><u>Some kids are comical</u> aren't they? <u>They all have their quirky little ways.</u></i></li> <li>• <i>Things when he was little which I'd noticed, but <u>never thought nothing of.</u></i></li> </ul>	Cathy reflected on early signs Jake's ASC, which, at the time, she had noticed, but was not concerned about: "it wasn't anything that alarmed me at the time". She normalised his "comical ways" at the time, but in hindsight, she shows a new understanding that Jake was probably different to other toddlers. A referral or diagnosis at this stage seems unlikely to have been helpful or necessary. Furthermore, these differences were unlikely to have been sufficient to warrant a diagnosis at the time, due to Jake's high level of functioning and low/no need for support, in line with DSM-5 criteria (Appendix 1).
<b>Chapter 4:</b> Primary Years: Infants (4-8 years)	<ul style="list-style-type: none"> <li>• <i>He was 8 when I took him to the opticians because the habits started.</i></li> <li>• <i>You speak to all other parents and they say, "Oh mine blinks their eyes, it is just a habit, it is nothing to worry about", so <u>you just accept that for a while.</u></i></li> <li>• <i>That became quite <u>annoying</u> [laughing] and <u>worrying</u> because you think "well, <u>why is he doing it?</u></i></li> <li>• <i>They just listened to what I said and <u>sent us away.</u></i></li> <li>• <i>They would just write it down, <u>not really say anything</u>, and say, "Come back next year".</i></li> </ul>	<p>Cathy seemed matter-of-fact and unemotional, perhaps indicating that she was only slightly concerned at this stage. Other parents normalised Jake's 'habits', but Cathy's statement "you just accept it for a while" indicates that her acceptance was short-lived. Although Cathy laughed that Jake's behaviours were 'annoying', she also described her increasing curiosity about the underlying reasons.</p> <p>Cathy appeared dissatisfied with the lack of support offered in relation to the diagnosis of Tourette's syndrome. Her recalling of professionals 'sending them away' and 'not really say anything' is a</p>

		comparator to what could have happened: this implies that Cathy would have liked them to <i>say something</i> or <i>do something</i> about her concerns.
	<ul style="list-style-type: none"> <li><i>I've never had a complete definite answer. But <u>I don't think there are definite answers</u> to a lot of these questions because I still think <u>it is still being researched</u></i></li> </ul>	Cathy reflected on the uncertainty, even from professionals, around the validity of the diagnosis of Tourette's syndrome in light of the ASC diagnosis.
<b>Chapter 7:</b> A traumatic time (13-15 years)	<ul style="list-style-type: none"> <li><i>From 13 to 15, we started hitting a lot of <u>problems</u>. So we had a lot of <u>battles</u> going on between those years. It was a <u>battle</u> with him. There was a lot of <u>arguments</u> about his attitude.</i></li> <li><i>It was <u>getting worse</u> and he was <u>getting bigger</u>.</i></li> </ul>	Cathy introduced the time period as "a traumatic time" and used the vocabulary of "problems", "arguments" and "battles". Her repeated use of the past continuous tense, "getting worse" and "getting bigger", connotes a sense of it becoming increasingly harder to cope.
	<ul style="list-style-type: none"> <li><i>You'd be like (sighs)... it was a <u>really, really difficult</u> time.</i></li> <li><i>We kind of <u>had enough</u> of it.</i></li> <li><i>It was <u>really, really hard</u>.</i></li> <li><i><u>Traumatic</u> to me (laughs). Oh!</i></li> <li><i>And I think Jake, it must have been <u>traumatic</u> for him as well.</i></li> <li><i>I used to be like "<u>Aagh</u>"!</i></li> <li><i>That was a <u>horrendous</u> night, the night he did that [ran away]... That was <u>horrendous</u>.</i></li> </ul>	Cathy sought to depict how challenging this period was for her (and the family). Her lexical repetition of adjectives "difficult", "hard", "horrendous" and "traumatic", as well as intensifiers, "really, really" are used to add emphasis. She also sighed, quoted herself as saying 'aagh' and even said that they'd "had enough", from which, I infer a sense of build-up to crisis point.
	<ul style="list-style-type: none"> <li><i>Every time we tried to tell other parents or like friends... it doesn't come across how bad it was.</i></li> <li><i>...people would say, "Well, he is just a teenager and yeah, ours are the same", and so you think "okay, fair enough", but then there would be another occurrence.</i></li> <li><i>His Dad and [I] completely fell out over it. Because they don't see our point of view.... They don't really see the problems.</i></li> </ul>	Cathy seemed frustrated that others (friends and family) didn't understand their difficulties or 'see' the problems. Again, Cathy's comparisons with other parents led to normalising Jake's behaviour, but her contrast of "but then there would be another occurrence", served to demonstrate her increasing realisation that things were different for Jake.
	<ul style="list-style-type: none"> <li><i>It was just a <u>nightmare</u>... me and my husband fell out, he ran away a couple of times when he was about 12 or 13.</i></li> <li><i>Things were very much <u>strained</u> between me and my husband</i></li> <li><i>I think the effect of how Jake was took its <u>strain</u> on us as a family, between 13 and 15, definitely.</i></li> </ul>	Cathy described this period as "a nightmare" and used the lexical repetition of "strain" to describe the effect of Jake's behaviour on family relationships, which emphasised the negative impact on the whole family at the time.

	<ul style="list-style-type: none"> <li>• <i>We couldn't deal with it, but we didn't know what we were dealing with. Which again, <u>if we had been diagnosed at a younger age, we would have been prepared. We could have got help and advice at the time, but we didn't have a clue.</u> We just thought he was rebelling, he was rebellious towards us. <u>We just couldn't deal with it. And I think Jake, it must have been traumatic for him as well.</u></i></li> </ul>	<p>Cathy suggested that an earlier diagnosis may have led to earlier preparation for adolescence and "help and advice" during this difficult and traumatic time. To emphasise the contrast, she said, "but we didn't have a clue", which further highlighted her sense of not being able to "deal with it" and her perception of the "trauma" perceived by Jake too.</p>
<p><b>Chapter 8:</b> The realisation and diagnosis (15-16 years)</p>	<ul style="list-style-type: none"> <li>• <i>That [Jake's lack of reaction to dog dying] <u>upset</u> us, because we were <u>devastated</u> by it and again, in my mind, you are thinking, "<u>well, I have reared a monster?</u>"</i></li> </ul>	<p>Cathy and her husband were upset by Jake's differences in emotional processing, empathy and reading of social cues, which were, at the time, unexplained, demonstrated by her powerful and dramatic question, "Have I reared a monster?" This highlights the impact for Cathy of living with the challenges of ASC, without the diagnostic label to understand. From this, I interpret that a slightly earlier diagnosis may have led to improved understanding and reduced parental distress arising from Jake's actions/comments at the time.</p>
	<ul style="list-style-type: none"> <li>• <i>I was <u>really worried</u> about him, about his state of mind.</i></li> <li>• <i>I was <u>frightened</u> to look at him sometimes... he seemed depressed to me and, as a parent, that is <u>quite worrying</u>... <u>You just don't know what is going on...</u> and it was <u>quite stressful</u> again at that time.</i></li> </ul>	<p>Cathy expressed her increasing concerns about Jake's mental health, as well as a sense of uncertainty and not knowing "what's going on". She uses the terms "worrying" and "stressful" to describe the impact on her at this time.</p>
<p><b>Nadir experience</b></p>	<ul style="list-style-type: none"> <li>• <i>When we reached that, just before he was 16, and we had already gone through <u>2 years of trauma</u>, and then <u>to realise, I realised what it was, but didn't know what I'd got to do about it</u> – that was really bad and then obviously the time following that was bad. I was <u>on anti-depressants myself</u> for that year.</i></li> <li>• <i>It was <u>a really tough time for all of us.</u></i></li> </ul>	<p>When asked to identify the worst part of the whole story, Cathy selected the period just preceding the realisation and diagnosis, describing it as "two years of trauma". Cathy disclosed that she was on anti-depressants, which illustrated the extent of the impact upon her own mental health at the time.</p>



Table A12: Cathy's experience narrative: Diagnosis phase

Timescales	Maria's Experience Narrative	My Interpretation and Commentary <i>What is the impact of the later diagnosis?</i>
<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	<ul style="list-style-type: none"> <li>• <i>[The school liaison officer said] "is this what he is like back at home? ...I don't know how you put up with him" because she could see part of what we were trying to tell people.</i></li> <li>• <i>[The SENCO and liaison officer] actually listened and understood for the first time... you just sometimes need someone to just know what you mean and understand.</i></li> </ul>	Cathy narrated interpretative remarks made by school staff, which served to vindicate Cathy's descriptions of the family's difficulties. This marks 'a realisation' for school staff about the extent of Jake's hidden difficulties. This seemed to be the first time that a professional has "seen", "listened" and "understood" Cathy's concerns, and it appears that she was grateful at the time.
	<ul style="list-style-type: none"> <li>• <i>I said to her, and it was just a flippant comment, I said, "Do you think that there is some OCD?"</i></li> <li>• <i>I didn't even mean it.</i></li> <li>• <i>And it just hit me because I thought I didn't even mean it... and for her to answer so quickly and thought that it was a serious comment.</i></li> </ul>	Cathy illustrated her tentativeness about her emerging suspicions of an underlying condition by reflecting: "it was just a flippant comment" and "I didn't even mean it". By contrast, she then expresses her sudden realisation, "it just me".
	<ul style="list-style-type: none"> <li>• <i>I couldn't believe it. Because I felt as though somebody must have written it about my son and about my life, there was everything there, absolutely everything, it described the feelings that we were going through, things when he was little which I'd noticed, but never thought nothing of, there was everything.</i></li> <li>• <i>What do I do? Somebody who is 1 month off 16... What do you do? How do you deal with that?</i></li> <li>• <i>That wasn't an easy time at all.</i></li> </ul>	Upon 'finding' autism and Asperger's syndrome on the internet, Cathy explained that this was the first time she could "relate" to others' experiences. She expressed disbelief at the discovery of Asperger's syndrome, which was immediately followed by her uncertainty, illustrated by her repetitive questions, "What do you do?" and "How do you deal with that?" Cathy made direct reference to Jake's age (16 years at the time) emphasising her sense of uncertainty and/or hopelessness.
	<ul style="list-style-type: none"> <li>• <i>Once he turns 16, it [referral] has to be with his consent... you lose all control at that age.</i></li> <li>• <i>If he had said, "no I'm not going", there wouldn't have been a damned thing I could do about it.</i></li> <li>• <i>Jake was under the impression that it was to do with family issues... but I knew it was because we thought he had got Asperger's.</i></li> </ul>	Cathy expressed a sense of fear, desperation and powerlessness, about Jake consenting to the ASC referral: "you lose all control at that age". She appeared anxious that if Jake did not consent, this may have formed a barrier to support for the family and securing an explanation. Cathy rationalised her mild level of deception to Jake, in him agreeing to the family therapy referral, whilst concealing the ASC aspect of the referral. This raises important practical implications about the importance of

		supporting families of older children (with or without a diagnosis) who may feel powerless as the young person's rights increase with age.
	<ul style="list-style-type: none"> <li>• <i>I was <u>gutted</u>. Because you just want it done yesterday (laughs)... we couldn't go until the April, so <u>we had to wait</u>.</i></li> <li>• <i>I <u>probably did cry</u> when I got that letter. I was like, "<u>oh no</u>", because I want to go now, not wait.</i></li> <li>• <i>I was so <u>disheartened</u> because <u>at the age of 16, what chance do they have of proving it or having some answers or having any help?</u></i></li> </ul>	In reaction to the referral and appointment, Cathy expressed disappointment at the waiting time (two months). Again, Cathy drew attention to Jake's age, "one month off 16", which adds to her sense of not knowing what to do. On this occasion, she explicitly asserted her anxiety and hopelessness that it might have been too late to help him or the family situation.
	<ul style="list-style-type: none"> <li>• <i>[At initial appointment] I was thinking, "<u>I don't believe this...</u>" We have half an hour, we have spoken about <u>stupid details which aren't anything to do with the problem</u> and we have talked for 15 minutes and to turn around and say, "<u>Oh I don't think...</u>"</i></li> <li>• <i>I was really <u>disappointed and upset</u>, and I thought "I've waited from January to April for nothing" and again, <u>I just didn't know where we were going to go.</u></i></li> </ul>	Cathy expressed frustration and disbelief that, after a lengthy perceived wait, the appointment seemed wasted. She appeared frustrated that the social worker, who led the appointment, dismissed the idea of ASC, without hearing, seeing or understanding their problems, or best hopes for the meeting. Cathy was left feeling "disappointed" and "upset" and expressed a lingering sense of uncertainty: "I just didn't know where we were going to go".
	<ul style="list-style-type: none"> <li>• <i>We went to see the autism diagnostic team... and it was all very <u>straightforward</u>.</i></li> <li>• <i>Looking back now, you think, "yeah, it didn't take that long at all", but it didn't feel like it at the time.</i></li> <li>• <i>You read on the internet other families who have <u>gone through it for years</u> and they haven't had a diagnosis, so <u>they have been fighting</u>, trying to prove to professionals for years.</i></li> <li>• <i>When we got the diagnosis and then looked back, <u>as traumatic as it was, that was pretty good really in comparison to what, I am sure, a lot of other people's stories are.</u></i></li> </ul>	When the referral to the autism diagnostic team was made, Cathy described the process as "very straightforward". Cathy seemed matter-of-fact and unemotional about the diagnosis itself, perhaps because the earlier 'realisation' evoked more of an emotional response. Cathy contrasted the experience of other parents/families (on the internet), who have had longer waiting times or more of a 'fight' to secure a diagnosis, and concluded that, despite the "trauma" experienced, the overall experience was "pretty good really".

Table A13: Cathy's experience narrative: Post-diagnosis and general reflections throughout the interview

Timescales	Maria's Experience Narrative	My Interpretation and Commentary <i>What is the impact of the later diagnosis?</i>
<b>Chapter 1:</b> Special baby' (Pre-birth/ pregnancy)	<ul style="list-style-type: none"> <li><i>I felt like I was accused of being a bad mother and I really wasn't because he was special, he was special from the start.</i></li> </ul>	Cathy seems to express a sense of vindication that she cannot be to blame for Jake's later behavioural difficulties, as Jake was somehow always 'special'.
<b>Chapter 8:</b> The realisation and diagnosis (15-16 years)	<ul style="list-style-type: none"> <li><i>[Things are] much better, I think.</i></li> <li><i>We have tried to be <u>more understanding</u>. If he wants to be in his bedroom, we are not so worried now because we know what it is.</i></li> <li><i>He makes <u>jokes about it</u>, whereas in the past... he <u>would have been nasty and aggressive</u>.</i></li> <li><i>He will sometimes go on about something and then <u>he realises he is doing it...</u> and then he'll say, "<u>Ooh, you know what I'm like</u>" and I'll go "yeah, I know what you are like".</i></li> <li><i>Whereas <u>in the past</u>, he would probably have continued to the point of where I would be like, "<u>you are driving me mad</u>" and it would <u>turn into an argument</u>.</i></li> </ul>	Overall, Cathy indicated that things are much better post-diagnosis. This primarily related to new levels of understanding for both Jake and his parents. Cathy used comparators to illustrate how things were worse prior to the diagnosis, including arguments, 'nastiness and aggression', and her sense that he was "driving her mad". By contrast, she expresses that she now feels less worried, and that the family are actually now able to joke about his differences and use humour to diffuse previously difficult situations, for example Jake saying "Ooh, you know what I'm like".
	<ul style="list-style-type: none"> <li><i>Again from what I've read, <u>the hormonal stage</u> is bad for a lot of teenagers, but a teenager with autism or Asperger's, it is very different again. I do believe from what I've read, from the age of 17 onwards, they <u>seem to have passed through that stage</u> which obviously, he has, and I can relate to that now.</i></li> </ul>	Cathy commented on her reading about the challenges and differences of ASC (particularly the influence of hormones at adolescence). She noted that she was able to relate to it, which significantly contrasts with her previous narratives that no-one understood her family's difficulties. The diagnosis appears to have been helpful for Cathy in this sense.
	<ul style="list-style-type: none"> <li><i>Jake knowing what it is [has] helped him a lot.</i></li> <li><i>I think he <u>understands himself better</u>.</i></li> <li><i>He then even mentioned things to me that he did that I wasn't aware of, but he was aware of but <u>didn't know why he did them</u>. It then <u>made sense to him</u> and he even</i></li> </ul>	Cathy described the positive impact of the diagnosis for Jake on his self-awareness and understanding, emphasised by her adverb 'tremendously'. Cathy suggests that Jake has understood himself better since the diagnosis, and with hindsight, he has understood his previous sense of 'being different'. I

	<p><i>spoke about <u>like a weight was lifted off his shoulders</u> because <u>he had always known that there was something</u>, but he didn't know what it was.</i></p> <ul style="list-style-type: none"> <li><i>[He said that] he always <u>felt sort of odd around other kids</u> and different. He had <u>never been able to understand why</u>, so if anything, I think <u>it has helped him tremendously</u>.</i></li> </ul>	<p>interpret that the later timing of the diagnosis may have been beneficial for Jake in some ways. He was sufficiently old, mature and able to research ASC on the internet himself and reflect upon what this meant for him. Perhaps if Jake had been diagnosed at a younger age, he may not have had the same level of understanding. Conversely, however, Jake may have benefitted from this information and self-understanding, prior to the 'traumatic time'. This highlights the need for further research with the CYP themselves about their own experiences pre-, during and post-diagnosis.</p>
	<ul style="list-style-type: none"> <li><i>Though it was later than I would <u>have liked</u>, at that point, they [SENCO and liaison officer] made me realise what was going on.</i></li> </ul>	<p>Cathy clearly stated that the realisation (and diagnosis) occurred "later than she would have liked".</p>
<b>Chapter 9:</b> Moving forward (17 years plus)	<ul style="list-style-type: none"> <li><i>I think [Jake] <u>understands himself better</u>... He is <u>more settled in himself</u> which obviously <u>makes us happier as well</u> (laughs).</i></li> </ul>	<p>Cathy described that Jake being "more settled" had a positive ripple effect for her and her husband.</p>
<b>Peak experience</b>	<ul style="list-style-type: none"> <li><i>I suppose the best was the point we are at now... because <u>Jake is happier and he is doing well</u>.</i></li> <li><i>We are <u>a lot happier as a family</u>.</i></li> </ul>	<p>When asked to select a 'high point', Cathy chose the current phase, post-diagnosis, in which "Jake is happier" and they are "a lot happier as a family".</p>
<b>General Post-diagnosis Reflections</b> (no particular timescales)	<ul style="list-style-type: none"> <li><i>It is <u>fascinating</u> looking back at last year when we went through the diagnosis... and thinking "<u>why didn't I know?</u>" and "I am his Mum, why didn't I know?"</i></li> <li><i>Then <u>obviously you have got the regrets</u> there when you are talking about things that you noticed... [and] thinking "Oh, why didn't I do anything?"</i></li> </ul>	<p>Cathy described a "fascination" with the whole experience, as well as a sense of "regret" and possibly guilt that, even though she was his mum, she didn't notice or act sooner. In my interpretation, Cathy's post-diagnosis emotions seem to be linked to her earlier absence of concerns (which may be explained by Jake's mild ASC presentation, rather than any omission on Cathy's part). Furthermore, the timing of Jake's later diagnosis may have led to an increased sense of guilt and regret, although Cathy did not explicitly indicate this.</p>
	<ul style="list-style-type: none"> <li><i>It <u>would have been so easy</u> for Jake to have gone to live with his dad, ended up staying there, <u>but it</u></i></li> </ul>	<p>Cathy repeated the phrase "it would have been so easy..." several times, although at first she doesn't give an</p>

	<p><u>wouldn't have been the right thing for him. Me and my husband would have ended up splitting up which wouldn't have been the right thing for us and that would have been it; the whole family would have been split apart. It would have been so easy.</u></p> <ul style="list-style-type: none"> <li>• <u>Then again, when we did finally get to see the social worker again it would have been so easy to have just walked out and say, "No it is really fine".</u></li> <li>• <u>We got to the age of Jake being 16 and never been picked up, and if it hadn't have been picked up then, as it was, which to be honest, was just by chance, it was a fluke really, but who knows, he could have been living at his dads happily and me and my husband would have been split up and that would have been it. We may never have known.</u></li> </ul>	<p>explicit comparator. She later implied that it would've been easy to miss the ASC completely, even at various stages following the realisation and referral, such as when the social worker initially dismissed the possibility of ASC. Cathy attributed the whole process to "chance" and "a fluke", which I interpret to indicate her sense of her helplessness and lack of control.</p> <p>Cathy described the potential disastrous consequences for Jake and the family if the ASC hadn't been recognised at all: Jake remaining with his Dad/Nan, and Cathy and her husband splitting up. She used the powerful comparator, "we may never have known" to accentuate the preferred outcome that ASC was identified.</p>
	<ul style="list-style-type: none"> <li>• <u>If it had have been picked up earlier, it would certainly have been a lot less traumatic.</u></li> <li>• <u>If there was more awareness, we probably wouldn't have gone through this.</u></li> <li>• <u>It came good in the end, however difficult this year was.</u></li> </ul>	<p>Overall, Cathy concluded that an earlier diagnosis would have made the situation "a lot less traumatic". She doesn't specify how much earlier, although previously she indicated that primary school "could" and the hospital "should" have 'picked it up'. Interestingly, at no point does she express the need for ASC to have been identified earlier than this (before age 6-8 years).</p>